Assessing New York State's Response to COVID-19 for People with Intellectual and Developmental Disabilities

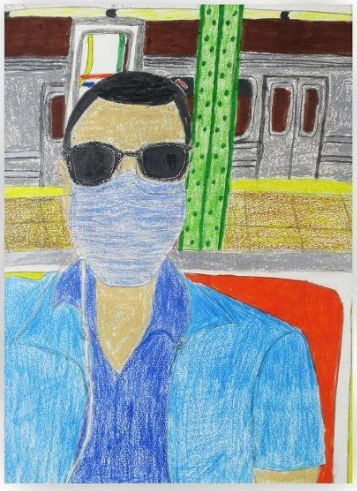
Prepared by the Developmental Disabilities Advisory Council
With Assistance from the New York State Developmental Disabilities Planning Council

November 2022

Report Cover Art Contest

The Developmental Disabilities Advisory Council, in partnership with New York State Senator John W. Mannion, sponsored an art contest for self-advocates to feature COVID-19-related art on the cover of this report. More than 40 self-advocates from across New York State submitted art work. Congratulations to the winner, ***Austin Cortez (front cover)*** and runners-up, featured below. To see a gallery of artwork from all the artists, visit www.ddpc.ny.gov.

Art by Monica Mzese



Art by Jason Valles

Art by Bob Pitts

ABOUT THE DEVELOPMENTAL DISABILITIES ADVISORY COUNCIL

The Developmental Disabilities Advisory Council (DDAC) was established pursuant to section 13.05 of New York State Mental Hygiene Law and is comprised of Governor-appointed volunteers from various stakeholder groups. They provide recommendations for statewide priorities and goals, comprehensive planning, resource allocation, and evaluation processes for state and local services for people with developmental disabilities.

DDAC Members:

Shameka Andrews
Geri Athenas
Daniel Brown
Nicholas A. Cappoletti
Janice Chisholm
Donna Colonna
Barbara DeLong
Janice A. Fitzgerald
Stuart Flaum
Gary S. Goldstein
Susan A. Hetherington
Vicky Hiffa
Lawana Jones
Paul Joslyn
Michele D. Juda
Suzanne Lavigne
John Maltby
Delores McFadden
Robert Pitkofsky
Margaret Puddington
Kai Roman
Sumantra Sarkar
Stephanie Speaker
Leah Steinberg
Melissa Stickle
Valeria Valdez
Meyer Wertheimer

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Foreword

COVID-19 was the first pandemic in over a century, and our world was not prepared for what was to unfold. The impact of an unknown virus was difficult to predict, policy decisions needed to be made quickly, and people's lives were in the balance. Hard decisions and tradeoffs were made in response to a public health crisis that ultimately had a significant impact on our society and people with intellectual and developmental disabilities (IDD).

On December 21, 2021, Governor Kathy Hochul signed New York State (NYS) Senate Bill S.6294A into law tasking the NYS Developmental Disabilities Advisory Council (DDAC) to evaluate the prior administration's response to the COVID-19 pandemic for people with IDD, specifically: review the state's response to the pandemic as it relates to the IDD community during the timeframe of March 1, 2020, to April 1, 2021; and provide recommendations to the NYS Legislature and Governor to improve the state's response to better address the needs of people with IDD in future emergencies.

It should be noted that no funding was provided to the DDAC to support this evaluation. Given the voluntary makeup of the DDAC and the significant resources required to conduct a report of this importance, NYS Office for People with Developmental Disabilities (OPWDD)Commissioner Kerri Neifeld connected the DDAC with the NYS Developmental Disabilities Planning Council (DDPC) who assisted us with the design, research and writing of this report.

Informed by a remarkable amount of stakeholder engagement, we have been able to tell stories of how the COVID-19 crisis, and the state's response to the crisis, impacted individuals living with IDD, their families, providers, and communities. This is not meant to be a scientific study, with statistical data validation, nor do we purport that the stories we have told are representative of everyone's experience. We do believe the experiences in which individuals, families, and providers faced challenges inform opportunities for improvement in planning and response.

This report will document the many actions the state took to protect the health, safety, and services of New Yorkers with IDD. It will also identify areas that were either not adequately addressed or presented challenges to people with IDD, their families, or providers. The members of the DDAC view this opportunity provided to us by the Legislature and the Governor as an opportunity to assess our preparedness and response to the pandemic, understand its impact on this vulnerable population, and create a plan that will strengthen our healthcare and long-term support services moving forward. While we may not be able to predict the next pandemic or natural disaster, we can be assured that at some point, there will be one.

Self-advocates, family members and providers have shared stories of unbelievable challenge and uncertainty, but also stories of remarkable endurance, creativity, and resilience. We are grateful for their participation in the preparation of this report and hope we have told their story well. We also would like to express our appreciation to those who risked their own health and safety to serve people with intellectual and developmental disabilities during this period.

The DDAC appreciates the assistance provided in the preparation and development of this report by the DDPC. We appreciate the support of Commissioner Neifeld and her administration, the Department of Health and the many people and organizations who contributed to the creation of this report.

Nick Cappoletti, DDAC Chair

Michele Juda, DDAC Vice-Chair

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Executive Summary

There is no doubt the first year of the COVID-19 pandemic was one of the most turbulent the world has faced in recent times, affecting every aspect of life. Unfortunately, people with intellectual and developmental disabilities (IDD) were disproportionately impacted by the pandemic, particularly those living in congregate settings. During 2020, COVID-19 was the leading cause of death for people with IDD, while it was the third leading cause of death in the general population.[1]"Compared to [people] without IDD, COVID-19 deaths were 1.6 times higher among [people] with intellectual disability, 1.5 times higher among [people] with cerebral palsy, and 2.1 times higher for [people] with Down Syndrome."[2] This disparity is due to several factors including but not limited to higher rates of comorbidities, risk of infection due to direct support needs, age and living in congregate residential settings, putting people with IDD at an elevated risk of poor outcomes from COVID-19. In fact, people with IDD living in group homes were four times more likely to test positive for COVID-19 and two times more likely to die as a result when compared to the general population.[3]

In accordance with enacted legislation, the Developmental Disabilities Advisory Council (DDAC), prepared this report to assess the state's response to the COVID-19 pandemic in relation to people with IDD for the period March 1, 2020 – April 1, 2021. After conducting a comprehensive environmental scan, analyzing pandemic-related data and receiving input from various stakeholders including self-advocates, family members, service providers, organizations representing underserved communities and Care Coordination Organizations (CCO), the DDAC concludes the following:

1. ***People with IDD and family members living in the community felt largely ignored by the state.***
   Approximately 70% of people served by the Office for People with Developmental Disabilities (OPWDD) live in the community; however, the state's response, with respect to guidance, personal protective equipment (PPE), testing and vaccinations was focused primarily on people with IDD living in certified settings. This is understandable given the high risk for exposure for people living in congregate settings, but people with IDD and their family members living in the community felt largely ignored by the state in its response to the pandemic, particularly regarding vaccines. People with IDD in the community were included in the "second wave" of vaccine priority only after significant advocacy by family members. Parents and caregivers for people with IDD were never prioritized by the state for vaccines.

[1] Landes, S.D., Finan, J.M., Turk, M.A., (2021). COVID-19 mortality burden and comorbidity patterns among decedents with and without intellectual and developmental disability in the US. *Disability and Health Journal*, https://doi.org/10.1016/j.dhjo.2022.101376.
[2] Ibid.
[3] Disability Rights NY, et. al. (2021). INVESTIGATORY REPORT: New York State's Response to protect people with intellectual and developmental disabilities in group homes during the COVID-19 pandemic.

2. ***OPWDD guidance fell short and lagged behind the needs of providers and the people they serve.***

   While there is no question it was "difficult to follow the bouncing ball" as one provider said regarding changing information and corresponding guidance early on in the pandemic, it was the overwhelming opinion of providers that guidance came well after the immediate day to day, or even hourly decisions that had to be made. Providers also expressed it would have been more helpful for the state to issue minimum standards and best practices, enabling providers to adjust to the many different needs of a particular setting or the particular needs of the people they serve. As we take a hard look at what was done and what can be improved, we must ask: could guidance have been timelier? Could the needs of the IDD community have been better anticipated, possibly avoiding the stress and time it took for parents, self-advocates and providers to repeatedly push for necessary health safeguards?

3. ***Guidance was difficult to access and understand.***

   OPWDD released a series of guidance documents during that first year of the pandemic to minimize exposure for residents and staff in congregate settings; however, most providers, self-advocates and parents did not find this guidance to be accessible or specific to the needs of people with IDD. In fact, in response to the DDAC's surveys, almost 80% of family members and 64% of self-advocates said guidance with consideration for people with IDD would be ***the*** most effective way New York could improve its public emergency response. There was no material in languages other than English, and no material provided through social media. OPWDD has Twitter and Facebook accounts but did not appear to use them to reach people with IDD and their families.

   Parents and self-advocates also said the data and information on OPWDD's website was difficult to locate and understand. Further, guidance issued by the state sometimes classified group homes in the same category as nursing homes and other times did not, which was confusing and frustrating for both providers and family members.

4. ***Underserved communities were mostly overlooked.***

   People with IDD and family members from underserved communities were mostly overlooked by the state in its response efforts. The state did not translate guidance into other languages and made little effort to conduct targeted outreach or partner with organizations in underserved communities to make sure information was distributed more widely.

5. ***Non-profit providers, for the most part, were not able to obtain PPE from the state at the beginning of the pandemic, jeopardizing the health and safety of staff and residents.***

   The state's initial efforts to provide PPE was only for OPWDD operated facilities. Voluntary providers were left scrambling in those first months to obtain necessary PPE, and given the shortage of PPE across the nation, had to resort to using whatever was available to

provide some protection for residents and staff. Providers reported being sent around in circles to obtain PPE and ultimately had to purchase PPE on their own.

6. Staffing shortages and program closures deeply impacted individuals and caregivers.

The closure of day programs at the beginning of the pandemic was especially difficult for both self-advocates and family members. Self-advocates felt increasingly isolated during this period and family members reported the stressors of having to continue to work while caring for their loved ones at home. In addition, as a result of chronic direct service provider (DSP) staffing shortages, family members were not able to hire staff to assist with the care of their family member, which was particularly stressful for parents of people with complex medical needs and those with significant behavioral issues.

7. Incompatible vaccination and visitation protocols created frustration.

Suspension of visitation at OPWDD certified settings had a significant adverse impact on both people with IDD and family members. Parents were particularly frustrated that while they and their family members were not allowed in person visits, staff working in those congregate settings, who were in close contact with their loved ones daily, were not mandated to be vaccinated and faced potential exposure from other residents or from their own family members and personal contacts.

8. The hospital discharge policy may have inadvertently accelerated the spread of COVID-19 for the IDD population living in certified settings.

The state's hospital discharge policy, which required providers to accept asymptomatic people with IDD back into the certified residence, had major health and safety implications for staff and residents and created significant operational concerns for providers. While the state's hospital discharge policy with respect to nursing home residents garnered a lot of press attention, this issue was largely ignored by the general public and media for people with IDD.

9. People with IDD were initially denied necessary supports while hospitalized which impacted their ability to access appropriate treatment.

The state's hospital visitation policy at the beginning of the pandemic, which did not allow hospital visitation unless it was medically necessary, or death was imminent was extremely concerning for family members. While this policy was initially revised to include a support person for pediatric and labor and delivery cases, it took significant advocacy on the part of family members to allow for support persons for people with IDD who were in the hospital. And even after the policy was revised, families reported being questioned or denied support visitation until they referred to or actually physically provided the revised policy.

10. Quality and accessibility of remote services were often an issue.

The emergency waivers provided during the pandemic, including allowing day and rehabilitation services to be offered remotely, and providing certain flexibilities to providers were very helpful, although the lack of access and ability for people with IDD to

engage in these services was repeatedly raised as an issue, along with the poor quality of these remote services.

11. ***The mental health of people with IDD and their caregivers greatly suffered during the pandemic.***
    A number of parents and self-advocates shared in focus groups the adverse impact the pandemic had on their mental health, including increased isolation, depression and anxiety. There is also anecdotal evidence that the prescription of anti-depression and other drugs significantly increased during the first year of the pandemic.

12. ***OPWDD was not transparent in sharing COVID-related data which limited planning efforts to prevent further exposure of COVID-19 among the IDD population.***
    A repeated theme heard from both parents and providers is that OPWDD initially did not share COVID-19 data on cases and deaths for people with IDD, and the data that was ultimately shared was very limited. Providers felt there were missed opportunities to identify trends so preventative measures could have been taken to mitigate the spread of COVID-19 among people with IDD in certified settings.

As a result of this assessment, the DDAC makes the following recommendations to the Governor and Legislature to improve the state's response to the IDD community during a public emergency:

<u>Create an Emergency Management Plan Specifically for the IDD Community</u>

- ***Include the IDD community in the COVID-19 Review RFP Issued by Governor Hochul on July 20, 2022, to include a comprehensive review of the COVID-19 response to the IDD community, what could have been improved and a plan for the future.***

- ***Ensure Emergency Management Planning is informed by voices that represent the racial, ethnic, and linguistic diversity of New York State, including multicultural providers.***

- ***Improve and coordinate communication to stakeholders.***

- ***Make considerations for the IDD community to address pandemic-related challenges faced by people with IDD, family caregivers and providers.***

- ***Make a plan to minimize the disruption of services during an emergency, especially for people with IDD living in the community.***

- ***Coordinate with local emergency management offices to educate and establish protocols on the needs of the IDD community so they are adequately prepared to provide local EMO resources.***

- ***Require mandatory training for all first responders to be able to understand and respond appropriately to the unique needs of people with IDD.***

- ***Streamline data collection and distribution during an emergency by creating an OPWDD data management system that is consistent with DOH data measures – user friendly and less burdensome for providers and includes an interactive emergency data dashboard for the public.***

Address Systemic Issues Exacerbated by the Pandemic

- ***Improve coordination between NYS agencies and local government offices during a public emergency, including a holistic review of all reports on the state's response to the pandemic that have been released thus far.***

- ***Address the chronic DSP workforce crisis by creating a task force to examine barriers and recommend actionable, short and long-term, solutions.***

- ***Reduce reliance on congregate care by examining regulatory, financial and administrative barriers to offering more independent housing options for people with IDD.***

- ***Maintain and expand flexibilities provided through emergency waivers.***

- ***Address the digital divide for people with IDD.***

- ***Collaborate with trusted partners to reach underserved communities.***

- ***Promote mental wellness of people with IDD, family caregivers and the workforce.***

Introduction

On December 21, 2021, Governor Kathy Hochul signed New York State (NYS) Senate Bill S.6294A into law requiring the DDAC to evaluate the state's response to the COVID-19 pandemic for people with IDD. This new law charged the DDAC with two major tasks:

1. Review the state's response to the pandemic as it relates to the IDD community during the timeframe of March 1, 2020, to April 1, 2021, and
2. Provide recommendations to the NYS Legislature and Governor to improve the state's response to better address the needs of people with IDD in future emergencies.

As a result of the legislation, the DDAC submits the following report to Governor Hochul and the NYS Legislature. For purposes of this report, any references to the state are referring to OPWDD as the regulating agency for DD providers and services, and the NYS Department of Health (DOH) as the state agency responsible for public health.

For a full text of the report legislation, see Appendix A.

In December 2020, the DDAC also provided a report to OPWDD called "Reflections on the Impact of the Events of 2020." This report, prepared by the DDAC's System Committee, was based on input collected from stakeholders within committee members' networks during the pandemic and highlighted concerns around communication, safety, health and mental wellness with strategies to address them. This document was an attempt by the DDAC to contribute stakeholder feedback in real time during the height of the pandemic.

Many of the findings in this assessment are consistent with those in the report submitted to OPWDD in December 2020.

The DDPC assisted with the preparation of this report, under the direction of the DDAC.

Methods of Analysis

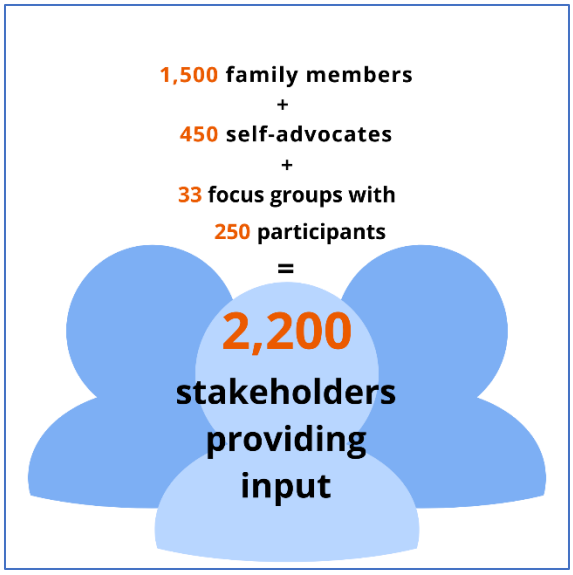
Over several months, the DDPC collected and analyzed vast amounts of information and stakeholder feedback on behalf of the DDAC to craft well-informed, meaningful recommendations to better address the needs of people with IDD for future state emergencies. Methods for gathering information included:

- Conducting a comprehensive environmental scan
- Cataloging pandemic-related guidance, policies and executive orders
- Creating a timeline of state outreach to stakeholders
- Compiling costs incurred by OPWDD related to pandemic response activities
- Analyzing pandemic-related data
- Distributing online surveys to people with IDD and family members

- Conducting focus groups with various stakeholders throughout the state

For a detailed timeline of guidance and outreach, see Appendix B and C.

For details on pandemic-related costs incurred by OPWDD, see Appendix D.



Survey and Focus Group Outreach

Significant effort was made to gather feedback as inclusively and from as many stakeholders as possible to accurately reflect the diversity of New York State and the IDD community. Family member and self-advocate surveys were distributed through various networks and shared through the DDPC email listserv and social media. The surveys were available online via SurveyMonkey and offered in five languages in addition to English including traditional Chinese, Simplified Chinese, Spanish, Bengali and Korean. DDPC notably conducted 33 focus groups with various stakeholder groups across New York State including:

- Organizations representing underserved communities
- Voluntary DD Service Providers
- Care Coordination Organizations (CCOs)
- Family members
- Self-advocates
- DDAC members
- Executive level OPWDD staff
- OPWDD staff at state-operated facilities

Significant efforts were also made to gather feedback from an array of subgroups within the IDD community. Surveys results were collected from individuals in various regions of the state and from various racial/ethnic backgrounds. DDPC conducted multiple regional focus groups with self-advocates to ensure statewide geographical representation. DDPC led focus groups with specialized groups of family members/caregivers to ensure all perspectives were gathered. These specialized groups included family members of people with IDD who lived in a certified setting, lived independently or with family members, received self-direction services, had complex behavioral needs or were medically fragile.

As a result of the surveys and focus groups, approximately 2,200 individuals with a connection to the IDD community in New York provided their input, personal stories, and suggestions for change. Participation in all surveys and focus groups was completely voluntary and anonymous.

New York State's Response to COVID-19

The first case of COVID-19 in New York State was announced by then-Governor Andrew Cuomo on March 1, 2020. In his statement, he said, "*There is no reason for undue anxiety -- the general risk remains low in New York. We are diligently managing this situation and will continue to provide information as it becomes available*."[4] On March 5, 2020, Governor Cuomo declared an Official State of Emergency in New York State to respond to the spread of COVID-19[5] and the state also began to issue infection control guidance. During the first year of the pandemic, New York State was facing an estimated $60 billion deficit due to additional costs from the pandemic. To offset this projected deficit, the state proposed a series of cost savings measures, including significant cuts to IDD providers in the state. These reductions were ultimately never implemented once the American Rescue Plan Act was enacted in March 2021.

Initial Pandemic Response

The DDAC cataloged and examined guidance issued by OPWDD and DOH and Executive Orders as they related to the IDD community and highlighted major guidance intended to minimize the risk of exposure between residents and staff.

According to OPWDD staff, the agency worked closely with DOH to develop guidance in accordance with CDC guidelines. Both DOH and OPWDD executive staff stated that OPWDD provided significant input on developing state guidance to meet the specific needs of the IDD population.

For a listing of guidance issued by the state pertaining to the IDD population, see Appendix B.

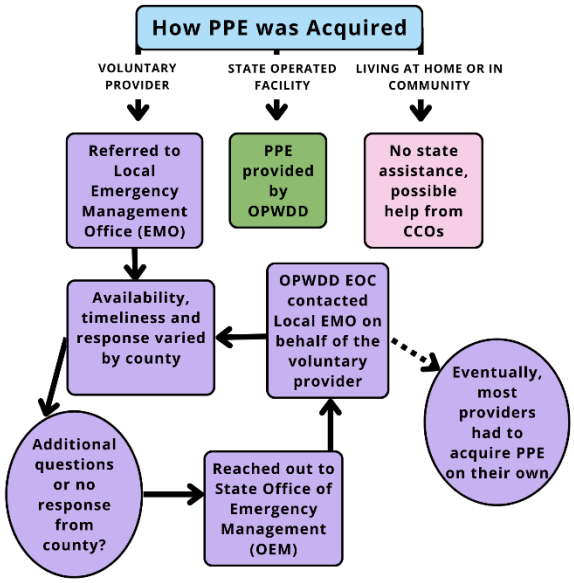
OPWDD, as well as other state agencies, incurred significant costs related to the pandemic. These costs included regular staff time devoted specifically to pandemic-related response efforts, overtime, PPE, tests and the state share of assistance provided to local governments. Based on financial documentation provided by OPWDD, these costs totaled over $177.9 million from March 1, 2020, through March 31, 2021.

For a detailed account of costs incurred related to the pandemic, see Appendix D.

[4] Governor Cuomo Issues Statement Regarding Novel Coronavirus in New York. (2020, March 1). Retrieved from www.ny.gov

[5] At Novel Coronavirus Briefing, Governor Cuomo Declares State of Emergency to Contain Spread of Virus. (2020, March 5). Retrieved from www.ny.gov

PPE Procurement and Distribution



According to information provided by OPWDD, the OPWDD Emergency Operations Center (EOC) coordinated PPE procurement through New York Responds, a web-based emergency management tool available to all state agencies. These requests were only in support of OPWDD operated facilities. The EOC also coordinated delivery/pickup of PPE and facilitated transportation to hubs across the state for distribution to OPWDD operated programs.

Voluntary providers and CCOs were referred to their local emergency management offices (EMOs) to acquire PPE; however, the vast majority of the time, there was no PPE available from the EMO. Some voluntary providers resorted to using cloth masks, rain gear and making their own hand sanitizer. People with IDD living in the community and their family members acquired PPE on their own, and on some occasions, were provided with PPE by CCOs when available.

Testing and Vaccinations

On April 17, 2020, the Governor's Office issued Executive Order 202.19 directing DOH to establish a statewide prioritization system for COVID-19 testing as there were limited tests available at that time. In response, DOH issued guidance on April 26, 2020, prioritizing symptomatic individuals in congregate settings, symptomatic individuals with underlying health conditions and individuals employed in congregate care settings among other identified populations (**Updated Interim Guidance Protocol for COVID-19 Testing Applicable to All Health Care Providers and Local Health Departments, DOH, 4/26/2020).** In Executive Order 202.30 issued on May 10, 20202, the state required routine testing of staff in nursing home facilities starting on May 15, 2020. Staff working in group homes were not subject to this testing mandate.

The emergency approval of the first COVID-19 vaccine was issued on December 10, 2020 **(Coronavirus Update, UD Food & Drug Administration, 12/11/2020).** People who lived in or worked at OPWDD certified homes were immediately given priority in Phase 1a of the state distribution plan. On December 11, 2020, DOH announced that staff and residents living in OPWDD operated facilities would be eligible to receive the COVID-19 vaccine beginning the week of December 21, 2020 (**Prioritization of Essential Healthcare and Direct Support Personnel as well as High-Risk Populations for COVID-19 Vaccination, DOH, 12/20/2020).** In a separate

memorandum, OPWDD announced that staff and residents in certified residential facilities were part of the initial phase of the COVID-19 vaccination program in New York, beginning the week of December 28, 2020 **(Interim COVID-19 Memorandum: COVID-19 Vaccine Prioritization in Certain OPWDD Certified Residential Settings, OPWDD, 12/22/2020**). It was noted in both announcements that the initial number of vaccines available would not cover all of this population. In addition, while vaccines were now made available to staff working in certified settings, DSPs were not required to get vaccinated. In DOH guidance released on January 5, 2021, vaccine availability was expanded to include staff with direct contact with people with IDD receiving OPWDD services in the community **(Interim COVID-19 Guidance: Week 4 COVID-19 Vaccine Prioritization in OPWDD Certified Settings, OPWDD, 1/5/2021).**

At that time, no vaccination provisions were made for people with IDD living in the community or their family members. People with IDD in the community and family caregivers with comorbidities were then included in phase 2 of vaccine distribution beginning February 14, 2021.[6]

Quarantining

DOH initially released quarantine guidance on March 9, 2020 (**2019 Novel Coronavirus (COVID-19) Interim Containment Guidance: Precautionary Quarantine, Mandatory Quarantine and Mandatory Isolation Applicable to All Health Departments, DOH, 3/9/2020).** On March 11, OPWDD released quarantine guidance for both OPWDD operated and certified settings (**Guidelines for Implementation of Quarantine and/or Isolation Measures at State Owned and Voluntary Providers in Congregate Settings, OPWDD, 3/11/2020**), which was the same as the DOH guidance.

Local departments of health were responsible for contact tracing and enforcement of quarantine orders. The Justice Center also assisted OPWDD in tracking individuals in quarantine for the purposes of supporting containment of the virus. Quarantine guidance was updated as guidance from the Center for Disease Control (CDC) evolved.

Closure of Day Programs

In guidance issued on March 17, 2020, OPWDD announced the immediate temporary suspension of day program services, closing in-person day programs across the state **(Immediate Temporary Suspension of Day Program Services, OPWDD, 3/17/2020).** OPWDD then issued guidance on April 24, 2020, outlining acceptable modifications to the service delivery system to allow for the use of virtual day habilitation services during closure **(Interim COVID-19 Guidance Regarding Day**

[6] Office of the Governor of New York. (2021, February 8). Governor Cuomo announces New Yorkers with comorbidities and underlying conditions can make appointments at state-run mass vaccination sites beginning February 14. Retrieved from www.governor.ny.gov.

Habilitation, OPWDD, 4/24/2020). Some providers were able to continue to provide day programming to people who also lived in their certified residences. On July 10, 2020, OPWDD provided standards to reopen OPWDD certified day programs **(Interim Guidance Regarding the Reopening of Day Services Certified by the Office for People with Developmental Disabilities, OPWDD, 7/10/2020).**

Suspension of Visitation in Congregate Settings

On March 18, 2020, visitation was immediately suspended at all OPWDD operated and certified settings (**COVID-19 Guidance for IRA's and Community Residences and Private Schools, OPWDD, 3/18/2020**).

Guidance was then issued on June 18, 2020, to allow for limited forms of visitation (**COVID-19: Interim Visitation Guidance for Certified Residential Facilities, OPWDD, 6/18/2020**). DOH then released further guidance on October 23, 2020, outlining standards for visitation according to zones, determined by rates of infection in the general population **(Health Advisory: All Residential Congregate Facilities, DOH, 10/23/2020).**

Hospital Visitation and Discharge

On March 18, 2020, DOH issued guidance suspending all hospital visitations, except where "medically necessary" or death was imminent (**Health Advisory: COVID-19 Guidance for Hospital Operators Regarding Visitation, DOH, 3/18/2020**). People with IDD, who typically would have a support person to ensure necessary communication and care, were excluded from this initial guidance. On March 21, 2020, guidance was amended to allow one support person for pediatric and labor and delivery cases, calling it "essential to patient care" (**Health Advisory: COVID-19 Guidance for Hospital Operators Regarding Visitation Updated Guidance regarding Obstetrical and Pediatric Settings, DOH, 3/27/2020**). Supports for people with IDD again were not included. These guidelines were eventually revised through DOH guidance issued on April 10, 2020, to allow for support persons for hospitalized people with IDD (**Health Advisory: Updated COVID-19 Guidance for Hospital Operators Regarding Visitation, DOH, 4/10/2020**).

In guidance issued on April 10, 2020, OPWDD required all certified residential facilities to accept any asymptomatic individuals being discharged from the hospital (**Health Advisory: Hospital Discharges and Admissions to Certified Residential Facilities, OPWDD, 4/10/2020**). In addition, no resident could be denied re-admission to a certified residence based on the suspicion they may still be COVID-19 positive. A hospital physician was responsible for determining if the resident was medically stable enough for discharge.

Stakeholder Communication

OPWDD communicated new and updated guidance primarily through its email listserv, virtual meetings with selected stakeholders, and the OPWDD website. According to OPWDD, for external stakeholders, such as self-advocates and family members, information was available by clicking a link on the OPWDD website to sign up for the OPWDD email distribution. In order to receive these updates, a person would need to sign up to be on the distribution list, have access to a computer and have reliable internet. OPWDD staff, providers, and other organizations automatically received updates through an internally managed contact list. Guidance was sent to all stakeholders if it was relevant to external audiences; operations-related guidance was only sent to those on the internal contact list. OPWDD also invested in a more robust email distribution software during the pandemic with the intent of improving COVID-related outreach to stakeholders. OPWDD shared significant efforts were made to communicate with stakeholders as much as possible via email; however, the agency was somewhat limited in the COVID-19-related information they could provide through the OPWDD website. OPWDD staff estimated there are approximately 40,000 subscribers currently on their email distribution list, a marked increase from the number of subscribers at the onset of the pandemic.

OPWDD also met virtually with a select group of stakeholders on a regular basis to provide updates on new and changing guidance and to gather feedback. In the early days of the pandemic, these meetings happened as frequently as multiple times a day and then tapered off as the months ensued. During these meetings, OPWDD would typically provide updates on guidance and fiscal information. As the pandemic continued, information on testing, vaccinations, data and other COVID-19 related information was also shared at these meetings. These meetings also provided an opportunity for OPWDD to hear feedback on challenges providers, family members and self-advocates were facing as a result of the pandemic.

These meetings were initially attended by provider associations and CCOs for planning purposes at the onset of the pandemic. OPWDD also included an association representing organizations that serve people with IDD in underserved populations in these virtual stakeholder meetings to specifically reach these communities. OPWDD stated the expectation was that these associations would then share the updates with their members. It was not clear how provider agencies who were not members of an association would be receiving this information. As the pandemic ensued, OPWDD eventually added self-advocates, parents, groups representing key stakeholders and other disability organizations to these stakeholder calls.

For a timeline of stakeholder outreach, see Appendix C.

Changes to Guidance as a Result of Stakeholder Feedback

According to OPWDD, the following changes were made to guidance and policy as a result of stakeholder feedback:

- Relaxation of fingerprinting and background check requirements to help with staffing shortages.
- Waivers to allow for billing and other flexibilities through Executive Orders and Appendix K so providers could continue to operate.
- Collaboration with DOH to change guidance to allow a support person or family member to accompany an individual with IDD that needed hospitalization during the pandemic.
- Allowance for visitation at OPWDD certified residences under certain circumstances.
- Collaboration with the Governor's Office and DOH to prioritize individuals with IDD for vaccination.

Waivers and Emergency State Plan Amendments

In order to provide fiscal stability to providers during the pandemic, OPWDD and DOH worked collaboratively to obtain emergency waivers from the federal Centers for Medicare and Medicaid Services (CMS) to allow for billing and other flexibilities. The Appendix K Waiver, a temporary measure that allows states flexibility in the use of funding during an emergency, is currently scheduled to end six months after the end of the federal public health emergency declaration. The Appendix K waiver was amended on April 20, 2020, to allow such flexibilities. Flexibilities include but are not limited to:

- Day and rehabilitation services can be delivered in non-certified sites
- Services can temporarily be delivered out of state
- Flexibility in the authorization of services, assessments and planning, when it is not possible to do in-person
- Certain habilitation services can be delivered via telehealth and phone
- Flexibility in required staff training
- Increase in fees for respite and community habilitation services
- Modifications for incident reporting, hand-written signature requirements and reduction for service duration minimums
- Allowing providers to give bonuses and vaccine incentives for DSPs

Assessing the State's Response to COVID-19 on New York's IDD Community

"We hit the ground running while we were jumping in the deep end of the pool." - Provider

March 2020 through April 2021 was indeed an unprecedented time in New York State's history. The impact of the COVID-19 pandemic stressed healthcare and social systems, as well as the financial stability of the State. New York was in a public emergency, battling an unknown virus.

Impact of COVID-19 on People with IDD

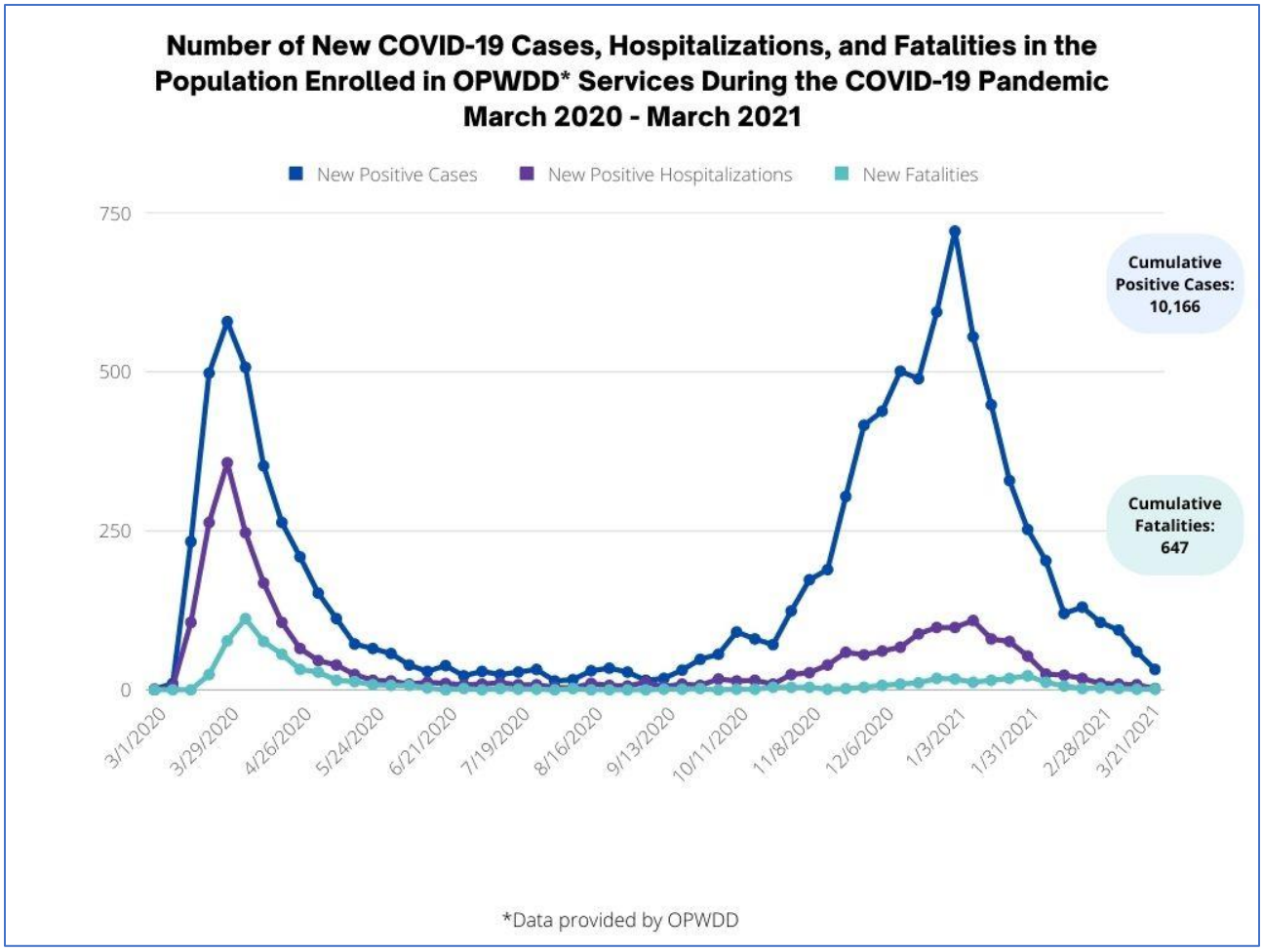
People with IDD were, and continue to be, particularly vulnerable to contracting COVID-19. One nationwide study revealed that having a disability was "the strongest independent risk factor for presenting with a COVID-19 diagnosis and the strongest independent risk factor other than age for COVID-19 mortality."[7] "Compared to [people] without IDD, COVID-19 deaths were 1.6 times higher among [people] with intellectual disability, 1.5 times higher among [people] with cerebral palsy, and 2.1 times higher for [people] with Down Syndrome."[8] These higher levels of infection and fatality are likely due to the fact that people with IDD face high prevalence of co-occurring conditions – including hypertension, heart disease, respiratory disease, and diabetes, which put them at elevated risk of poor outcomes from COVID-19[9]

According to data provided by OPWDD, between March 2020 and March 2021, more than 10,000 individuals enrolled in OPWDD services contracted COVID-19, and of those, 647 died as a result. For individuals living in certified residential settings, as of April 1, 2021, almost 50% of the cases and almost 75% of deaths occurred in New York City or the surrounding areas.

[7] Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., Stephens, M. (2021). The devastating impact of COVID-19 on individuals with intellectual and developmental disabilities in the United States. *Innovations in Care Delivery.* doi: 10.1056/CAT.21.0051NEJM.

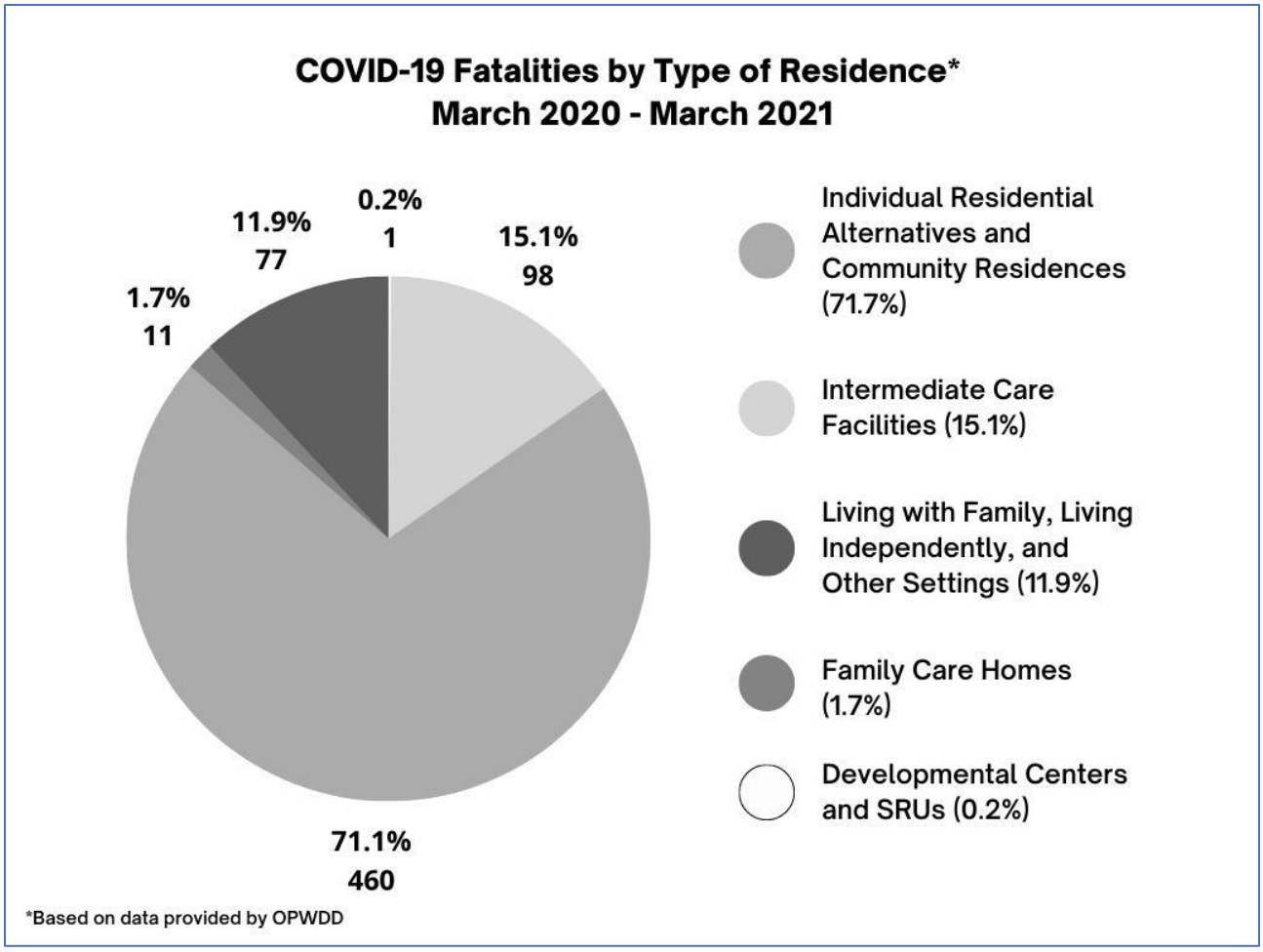
[8] Landes, S.D., Finan, J.M., Turk, M.A., (2021). COVID-19 mortality burden and comorbidity patterns among decedents with and without intellectual and developmental disability in the US. *Disability and Health Journal*, https://doi.org/10.1016/j.dhjo.2022.101376.

[9] Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., Stephens, M. (2021). The devastating impact of COVID-19 on individuals with intellectual and developmental disabilities in the United States. *Innovations in Care Delivery.* doi: 10.1056/CAT.21.0051NEJM.



From March through October of 2020, there was a 91% increase in overall deaths of people with IDD in OPWDD certified settings as compared to the same time period in 2019, with COVID-19-related deaths accounting for 43% of deaths in certified settings.[10] One provider reported to Disability Rights New York that "at the height of the pandemic, they had 50% of their residence quarantined."[11] The following graph provides details on where people with IDD who died from COVID-19 were living in NYS. While about 30% of people with IDD in New York reside in an OPWDD certified residential setting (for example individual residential alternatives, intermediate care facilities, developmental centers etc.), people living in those settings accounted for 86% of COVID-19 related fatalities, according to data provided by OPWDD. Conversely, individuals living in the community represent 70% of the IDD population in NY and accounted for approximately 14% of the fatalities.

[10] Disability Rights NY, et. al. (2021). INVESTIGATORY REPORT: New York State's Response to protect people with intellectual and developmental disabilities in group homes during the COVID-19 pandemic.
[11] Ibid.



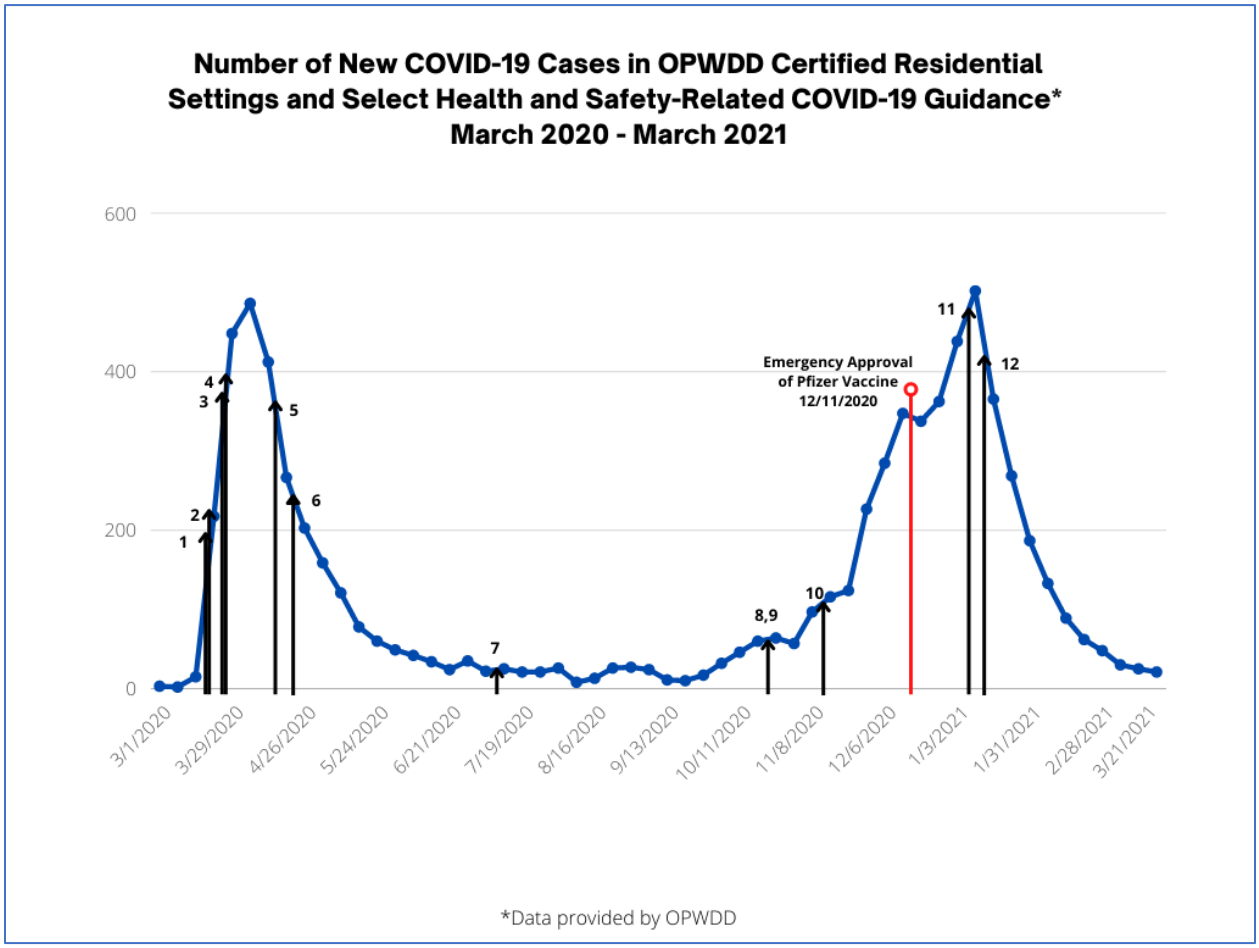
Clearly people with IDD living in a congregate setting were much more likely to become infected with COVID-19 and therefore, die from complications from the virus than people with IDD living in the community. The case rate for people living in New York's group homes was also disproportionately high when compared to the general population. Based on data assembled during the first three months of the pandemic, it is estimated that people with IDD living in group homes were **four times** more likely to test positive for COVID-19 and **two times** more likely to die as a result when compared to the general population.[12] Although this demonstrates the vulnerability of people with IDD living in a congregate setting, it should be noted that testing was far more accessible to people living in group homes than the public at large during this time.

[12] Disability Rights NY, et. al. (2021). INVESTIGATORY REPORT: New York State's Response to protect people with intellectual and developmental disabilities in group homes during the COVID-19 pandemic.

Impact of Health and Safety Guidance on People with IDD

"People with intellectual and developmental disabilities (IDD) are a vulnerable health population that does not receive adequate attention within public health research and intervention/efforts."[13]

The following chart and key depict the number of new cases for people with IDD living in certified settings from March 2020 through March 2021 along with select guidance issued by the state intended to reduce the spread of the COVID-19 virus during that time. It should be noted that not all guidance issued by the state during that time is included on this chart.



[13] Turk, M., Landes, S., Formica, M., Goss, K. (2020). Intellectual and developmental disability and COVID-19 case fatality trends: TriNetX analysis. *Disability and Health Journal, 13.* 100942.

Selected Guidance*

1.	3/17/2020 Email memo announcing closure of day programs
2.	3/18/2020 COVID-19 Guidance for IRA's and Community Residences -- Visitation is suspended immediately
3.	3/25/2020 Staff Guidance for the Management of Coronavirus (COVID-19) in Facilities or Programs Certified by OPWDD -- Staff assignments to limit exposure, do not "float" staff, visitation suspended, health checks, other ways to limit exposure
4.	3/28/2020 COVID-19 Protocols for Direct Care Staff to Return to Work -- Conditions to return to work if you have been infected or exposed
5.	4/10/2020 Interim Guidance Regarding the Use of Telehealth/Covid-19 -- Authorizes use of telehealth, when and how to provide telehealth, do not need to change life plans due to change in mode of delivery, billing guidance
6.	4/20/2020 Appendix K Waiver Amended
7.	7/10/2020 Reintroduction of Individuals to Certified Residences After Extended Home Visits -- Conditions to be met to return
8.	10/23/2020 Health Advisory: All Residential Congregate Facilities --Limitations on visitation in "Red, Yellow, and Orange" Zones
9.	10/23/2020 Interim COVID-19 Guidance: Designated Cluster Mitigation -- Guidance based on transmission "clusters," Red, orange, and yellow, day programs open in yellow
10.	12/22/2020 Interim COVID-19 Memorandum: COVID-19 Vaccine Prioritization in Certain OPWDD Certified Residential Settings -- Order to follow 12/20/20 DOH guidance in order to prioritize vaccines for people with I/DD
11.	1/5/2021 Interim COVID-19 Guidance: Week 4 COVID-19 Vaccine Prioritization in OPWDD Certified Settings -- Expands vaccine prioritization to other staff who have regular direct contact with service recipients -- not transportation staff
12.	1/14/2021 Interim COVID-19 Guidance: Week 4 COVID-19 Vaccine Prioritization in OPWDD Certified Settings REVISED -- Inclusion of Transportation Staff

***Data selected from 88 IDD-related guidances issued by OPWDD, DOH, and Executive Orders from March 1, 2020 - March 31, 2021 -- See appendix for complete list of guidances**

While it is difficult to attribute the direct impact of each state-issued guidance on the number of new COVID-19 cases in OPWDD certified residential settings, the chart raises the following questions:

1. Could the state have done anything to release guidance in a timelier way to keep up with the changing dynamics of the pandemic?

2. Did the state miss opportunities to plan ahead, particularly during the summer lull in new cases knowing an approved vaccine was forthcoming?

3. Did the state keep visitation and other restrictions in place for too long as pandemic conditions were improving?

These questions were also raised during multiple stakeholder groups. Exploring the answers to these questions presents an opportunity for the state to be more strategic and planful in the issuing of guidance during future public emergencies to minimize the impact of a public health emergency on people with IDD.

Self-Advocate and Family Member Feedback

State Guidance and Communication

While staff from both OPWDD and DOH confirmed they worked collaboratively to consider the needs of people with IDD in state issued guidance, this was not the perception of key stakeholders. The overwhelming majority of people with IDD in New York live in the community; however, self-advocates and family members expressed in focus groups that people living in the community and their families were, for the most part, left out of any response or guidance issued at the state level, especially guidance issued directly by DOH.

CCO staff, self-advocates, and their family members stated they were often left on their own to meet any service needs or were directed to contact their local department of health or emergency management office. One CCO Executive shared that CCOs jointly took the initiative to create a risk assessment and service identification tool to meet the needs of their population since they did not feel the state would be able to offer any assistance with this necessary task. Self-advocates and family members reported local government agencies were frequently unable to meet any expressed needs, or they were completely unaware of the needs of individuals with IDD living in the community. This was especially perilous if the person was medically fragile, had complex behavioral needs, or was in an active emergency.

"The state operated residences always got preferential treatment over those of us living at home or in a non-group setting."
- Self-advocate

Nearly 90% of self-advocates and 70% of family members responding to the DDAC report survey thought providers in certified and community-based settings followed COVID-19 health and safety guidelines. About 50% of family members responding to translated surveys agreed. While more than half of self-advocates and family members responding to the survey said they did not have any barriers to accessing PPE, participants in focus groups shared numerous stories of challenges with masking compliance. Family members in focus groups said masking guidelines, in most cases, were strictly enforced, especially in medical offices, and there were no special accommodations made for people with IDD who were unable to or could not tolerate wearing a mask. In some cases, people with IDD were refused medical care as a result of their inability to wear a mask.

Nearly 90% of self-advocates and 70% of family members responding to the DDAC survey thought providers in certified and community-based settings, followed COVID-19 health and safety guidelines

"My son, he also has autism, and he has a lot of sensory limitations and every time we would go to the doctor, we would lose the appointments because they would say 'how is your son not wearing a mask' and I would try to explain to them that due to his limitations and disability he could not wear the mask." - Family member

Nearly two thirds of self-advocates responding to the DDAC survey relied on family and/or friends as their primary source of pandemic-related information.

Nearly 80% of family members and 64% of self-advocates responding to the DDAC survey said guidance with consideration for people with IDD would be the most effective way New York could improve its public emergency response.

Most stakeholders in focus groups and surveys, including self-advocates, parents and providers, did not find the state's communication strategy and guidance to be accessible. Only 18% of family members and 13% of self-advocates responding to the DDAC Report survey relied on OPWDD for pandemic-related information. They felt the information and data provided on the OPWDD website tended to be difficult to locate and understand. Self-advocates and family members in focus groups said the way the data was presented was not helpful nor informative, and suggested a searchable, interactive dashboard would be more beneficial.

For the IDD population living in the community, OPWDD relied on service providers, CCOs, and Care Managers to provide necessary health and safety updates, which did not always happen, often leaving people with IDD and family members in the dark. Stakeholders with low literacy

levels or lack of internet access reported in focus groups they had difficultly both finding and comprehending guidance.

"Make literature in simple language. The OPWDD website is not that simple."
- Self-advocate

In focus groups, self-advocates and family members reported that when they had questions on state guidance, there was generally little to no response from OPWDD Central and Regional Offices; however, it was noted in focus groups that some OPWDD Regional Offices were more responsive than others.

"I used to get information through meetings held by [CCO] on a regular basis, no other care providers did that. There was a lot of confusion for those who self-direct because agencies had to interpret documents, not everyone got the same information. It was dependent on the relationship you had with your broker." – Self-advocate

Focus group participants who were also involved in OPWDD-led pandemic update calls provided additional feedback, noting while their persistent advocacy eventually resulted in changes to data being shared on stakeholder calls, they often felt dismissed or unheard. They also continuously pushed for "lessons learned" in real time that could have been leveraged in other areas of the state before or during regional spikes; however, stakeholders said that information was not made widely available. Focus group participants also questioned how OPWDD identified who should be on these calls and if OPWDD could have improved the dissemination of information, and the breadth of feedback, if they included more representatives from stakeholder groups. Some focus group participants did share that OPWDD, when requested, expanded the number of stakeholders on these calls, including additional provider agencies, self-advocates and parents.

"The information about New York's response to COVID-19 in relation to people with IDD, was not easily available. Everyone was asking one another and did not know any one source where all information is available." - Self-advocate

PPE, Medical Equipment and Staffing Shortages

While the majority of family members and self-advocates said they always or usually were able to access PPE, shortages and access to essential medical equipment, medication and staff support especially impacted medically fragile people with IDD according to family members in focus groups. Parents shared stories of having difficulty getting supplies such as oxygen and tubing for ventilators and receiving phone calls from local departments of health that their child's equipment was subject to collection and redistribution to hospitals to combat shortages. Parents of medically fragile people with IDD shared stories of resourcefulness as they struggled to get supplies. Given the world-wide circumstances of medical supply shortages at the beginning of the pandemic,

"Our daughter is medically fragile, and we were unable to get nursing support."
- Family member

this does not come as a surprise; however, with the potentially catastrophic outcomes for people with IDD acquiring COVID-19, this was truly a terrifying time for people with IDD who were medically fragile and families.

Staff shortages were particularly stressful situations for family members/caretakers who were essential workers or were sick themselves and needed to quarantine and lost essential supports to care for their loved ones in the home. The shortage of staff was a recurring theme in parent focus groups and created significant challenges for family members and caretakers.

"Our son ended up (along with our family) being admitted to Strong medical Psych in Rochester because there were no programs, no in home services, no help at all. The WORST thing that happened was having him stay in this hospital setting with doctors that just pushed more and more medications that were making it worse – we ended up taking him home and medically stripping him ourselves. The worst experience for our son and family. We are still waiting, a year later, for help from certain crisis programs." – Family member

Approximately 60% of family members responded to the survey that they were rarely or never able to get back up support if they needed it, and less than half of parents responding to the translated surveys were also unable to get support. In addition, working parents with school-aged children reported the stress of being unable to hire community habilitation or respite workers during the school day because that was not allowed during school hours, even though their children were not in school during this time.

Almost 60% of parents responding to the DDAC survey said that they never or rarely were able to get back up support if they needed it

Providers and CCO's repeatedly mentioned staffing as a major issue in focus groups, emphasizing staff would try to assist whenever possible, but continual shortages made it difficult to meet all support needs. When feasible, staff from closed day programs were redirected to deliver food, perform well checks and do what was necessary to fill the unfortunate gaps in services.

Parents and caregivers of family members who self-direct shared frustrations over the lack of flexibility in hiring staff. If parents and caregivers found workers available for respite but had funds available for community habilitation, they were not allowed to hire respite staff without changing their budget, which is a time-consuming process. Family members and self-advocates reported the shortage of staff also impacted self-directed services, expressing they felt unsupported and abandoned.

"Throughout the pandemic, to this day, I expressed need for respite services and was never given any info except there's nothing. I found a parent operated social program on my own and a weekend respite program that was open throughout the pandemic."
- Family member

Even though the state allowed for the re-opening of day services on July 10, 2020, the

"My son has not been able to return to his Day Program due to lack of staffing. He has regressed several years which is very discouraging. No programming for 2+ years and he's still waiting!!!!!!!"
- Family member

shortage of staff has prolonged the re-opening or greatly reduced the capacity of many day programs. As of April 2021, almost 50% of agencies reported having to greatly reduce or close programs due to staffing shortages and 40% had yet to re-open.[14] "In the past three years, 130 OPWDD operated group homes across the state were 'temporarily suspended' due to staff vacancies."[15] Family members of people with complex behavioral needs, as well as mental health needs, reported program closures due to staff shortages have been detrimental to the stability of their loved ones. In some cases, people with IDD faced regression or became self-injurious and needed supports but were not able to access them.

"Shortages of well-qualified and trained staff to provide the much-needed services for comm hab and respite continue to be of major concern and a real roadblock for moving forward. I hope for the restoration of services and activities for our population so that they, and we their families, can begin to see a little more light at the end of the tunnel. I will continue to hope for better days to come." – Family member

Testing and Vaccinations

In focus groups, both self-advocates and family members living in the community shared challenges with accessing vaccines for people with IDD at mass vaccination sites as the environment of the sites were sometimes stressful for people with IDD and led to behavioral issues. Some family members of people with IDD who are also medically fragile expressed concerns with bringing their compromised loved one to a mass vaccination site or were physically unable to do so. In some localities, special hours or clinics were set up to help make people with IDD more comfortable; however, these special arrangements were not available statewide. In addition, people with IDD who are also homebound reported facing initial challenges with getting access to vaccines and testing in their homes until they became more widely available and accessible.

It should be noted that OPWDD made concerted efforts to assist people with IDD in receiving the vaccine such as allowing certain provider agencies to be able to administer the vaccine. OPWDD also advocated for an IDD set aside vaccine supply at the local level, which allowed counties to provide specialized IDD clinics as a result.

In several focus groups, family members who were caregivers for compromised people with IDD living in the community shared frustration they were not prioritized for access to tests and

[14] New York Disability Advocates. (2021). 2021 NYDA Workforce survey.
[15] Lyons, B. (2022, August 1). Staffing shortages continue to spur group home closures. *Times Union.* www.timesunion.com

vaccines. One participant shared she had a son with IDD at home and did not qualify to get a vaccine early. She felt she should have been a priority. Family members of people with IDD expressed the importance of getting early access to vaccinations as they were often the sole caregiver when school, community-based services and in-home services were unavailable. If they were to contract the virus, they could expose their loved one, get extremely ill, or worse, die, and leave their loved one without a caregiver. Family members served as essential caregivers during the pandemic as programs closed; however, they were not given the same vaccine prioritization as DSPs and other staff with direct contact with people with IDD in both residential settings and the community.

Another repeated concern raised by parents in focus groups was the lack of a vaccine requirement for DSPs. In some cases, family members discontinued in-home services for their loved one because their DSP refused to be vaccinated. According to a survey of New York DSPs, 98% of employers did not require vaccinations and only 13% of employers offered a financial incentive for getting vaccinated.[16]

Closure of Day Programs

They told us we had to stay home, and it made me feel sad because I couldn't see my friends." – Self-advocate

The closure of Day Programs at the beginning of the pandemic meant that people with IDD relying on in-person services and supports lost their daily routine and skill-building opportunities, which in some cases resulted in behavioral, mental and/or social regression. Self-advocates frequently reported feeling isolated.

Family members working from home shared in focus groups they struggled to care for their loved ones while also meeting work-related obligations, especially in cases where their loved one with IDD was medically fragile, had complex behavioral needs or both. One parent shared, "Our family is STILL in crisis as a result of the pandemic. I was forced to leave my job [as a county employee] as of July 1, 2020, when FMLA could no longer protect my position and all of my paid and unpaid leave time was exhausted."

"It was unbelievable, what a hardship it was – I threw out my back – I barely could keep my job."
– Family member

[16] National Alliance for Direct Support Professionals. (2021). Providing support during the COVID-19 pandemic: Direct Support Workforce 12-month follow-up survey - New York version. www.nadsp.org

Suspension of Visitation in Congregate Settings

"It put a stop to family visits which was upsetting and changing daily routine/schedule was a big adjustment for us all." - Self-advocate

Loss of visitation had a significant impact on both people with IDD and their families/caregivers. Over one-third of family members responding to the DDAC survey said they 'disagreed' or 'strongly disagreed' with visitation guidance. Of those who responded they 'disagreed' or 'strongly disagreed', there were mixed responses as to whether the visitation guidance was over-reaching or did not go far enough.

"Unable to visit my family members and being isolated was the worst part of the COVID Pandemic!"
- Self-advocate

People with IDD missed their families and vice versa. Family members reported feeling uneasy without seeing their loved one in-person to check on their well-being, citing concerns about their care and safety with reduced and revolving staff that might be unable to attend to or unaware of specific needs and behaviors. Providers utilized virtual meeting platforms, telephone calls and outdoor meetings as restrictions began to lift to safely accommodate visitation. Some parents reported advocating for more visitation accommodations, and while some providers granted those requests, some did not.

"It was difficult for me not being able to visit with my son. Thank God for video call. I was still missing the physical visit with him. I only saw him once a month."
- Family member

While self-advocates and parents acknowledged that some level of visitation restriction was necessary in the beginning of the pandemic to maintain the health and safety of residents, there were differing opinions on the efficacy of the visitation policies and the length of time they were kept in place. In addition, family members expressed frustrations that DSPs, while also exposed to transmission from the general public, were permitted to continuously enter and then leave the facility. Parents expressed that they should have been able to visit with their loved ones with the same mitigation protocols applied to staff. When OPWDD released initial guidance on limited visitation, self-advocates and parents reported that some providers chose a slower, more cautionary approach to expanding visitation. One parent shared during a focus group that she could not visit with her child until nine months into the pandemic.

"I would drive there and ask to see him through the window. I considered calling 911 from his behavior that I could see through the window."
- Parent

"Parents should be permitted with proper PPE to see their children. I would see my son on Facetime at his best, not at his worst. I need to see him at his worst to know if he is being well-taken care of." - Parent

Hospital Visitation Policies

In the initial days of the pandemic, hospital visitation was also of extreme concern. Support professionals and family members were not permitted to accompany people with IDD, who could not advocate for themselves, during hospitalization or emergency transportation. After significant stakeholder advocacy, this was eventually addressed through revised guidance. Several parents shared during focus group discussions that their loved one with IDD was still denied this support option even after the revised guidance was issued. Some reported keeping a copy of the guidance with them and having to show medical and emergency staff when their presence was questioned. Some CCOs also reported they had to escalate non-compliance issues to OPWDD and DOH on the behalf of families, when they continued to be denied access to their loved one in the hospital, even after the guidance was issued.

The DDAC heard anecdotal stories of families that feared their loved one with IDD died while they were hospitalized because they were unable to advocate for themselves and were initially not allowed a support person.

Telehealth, Telemedicine and Virtual Services through Waivers

"I do not like remote learning, so I lost connections to my friends and program. I am still not in any program and that is unacceptable, I want to be back with peers." - Self-advocate

Through Appendix K and other waivers, many provider agencies offered services through telehealth, telemedicine or virtual programing; however, some people with IDD shared in focus groups they lacked access to devices or reliable internet. Although parents indicated in focus groups they appreciated virtual programming as an option, many people with IDD had difficulty engaging in remote activities. In addition, parents said the quality of the virtual programming was lacking, with one parent sharing the day program for her 28-year-old son showed cartoons every day.

An organization providing services in an underserved community shared that most families they serve did not have access to more than one device or to WIFI.

An organization providing services in an underserved community reported most families they serve did not have access to more than one device or to WIFI. The families would have to choose between the parent working from home or the child participating in virtual schooling. Most of the time, the child would be missing out on their education. One CCO shared they had to loan family members with no internet access or phone, smartphones and other devices to provide virtual support and emergency contact capability.

"The pandemic was very difficult for my son with IDD. It increased his anxiety and led to isolation. There were virtual social events that he did attend but being on the computer is not the same as in-person. His social skills suffered, and anxiety increased." - Family member

Underserved Communities Feedback

Unserved and Underserved communities include "populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life."[17]

Although families and people with IDD in underserved communities faced many of the same challenges as other communities throughout the state, they did encounter additional significant challenges with accessing COVID-19-related information.

"[We were] immediately put in position to take the lead on gathering information from OPWDD, DOH and other agencies, but had to condense, translate, and communicate it in a culturally appropriate way. Immediate challenges included trying to decipher all the safety protocol/testing/vaccine information coming in and translate it through effective mediums" – Provider in underserved community

According to interviews with organizations representing underserved communities, communication and consideration for underserved communities was almost entirely overlooked by the state. They reported guidance was often not provided in plain language or translated into plain language other than English. For people with IDD and families who were new Americans or living in an underserved community, it was particularly challenging to gain access to information. Most relied on service organizations in their communities to share information and provide translation; however, not all individuals and families were connected with such organizations. According to parents and caregivers that responded to the survey translated into Korean, less than 10% received pandemic-related information directly from OPWDD.

Organizations in underserved communities also noted that the state did not utilize culturally accessible communication platforms nor partner with organizations in underserved communities to distribute information more widely. Community organizations shared they sought out various outlets on their own to disseminate information, such as WeChat and ethnic radio, to ensure it was easily interpreted by families and people with IDD. This failure on the state's part to conduct

[17] Retrieved from Public Law 106-402 106th Congress October 30, 2000 (acl.gov)

targeted outreach to underserved communities was also acknowledged by OPWDD officials during one of the focus groups.

Organizations in underserved communities reported reaching out to OPWDD regional staff on how to obtain PPE, and they were referred to their respective local emergency management office. One organization in an underserved community said they had such difficulty obtaining hand sanitizer that they resorted to making their own. Almost 50% of family members that responded to the survey translated into Simplified Chinese reported they did not have consistent access to PPE or were not always able to find PPE.

Voluntary Providers and CCOs Feedback

State Guidance

"Chaotic, confusing, and scary quite frankly." - Provider's description of guidance

"As a provider, if you did not take individual action, the results would have been worse." - Provider

Both providers and CCO's shared in focus groups that OPWDD did not issue guidance in a timely manner, and the guidance tended to lag behind the changing circumstances of the pandemic. Providers in focus groups indicated they had to implement their own safety protocols, in advance of directives from OPWDD, in hopes of being proactive to stop the spread of the virus in their facilities. "For example, it was not until April 28 [2020] that OPWDD finally released guidance clearly recommending that … [facility staff with COVID-19 related symptoms or a fever should be sent home immediately] …. By this time over 300 people with IDD residing in IRAs or ICFs had died according to the Justice Center data…"[18]

Providers perceived that guidance was frequently issued at "5 o'clock on a Friday"

Providers also repeatedly expressed their perception that guidance was frequently issued at "5 o'clock on a Friday" causing them to scramble over the weekend to strategize how they could change procedure and staffing to remain in compliance. Also, guidance was often released to providers and family members at the same time. This presented challenges, particularly when visitation guidance was scaled back, as families were showing up at facilities before providers had protocols in place to accommodate them. Providers expressed concern that OPWDD policies were

[18] Disability Rights NY, et. al. (2021). INVESTIGATORY REPORT: New York State's Response to protect people with intellectual and developmental disabilities in group homes during the COVID-19 pandemic.

issued without understanding their impact, causing a disconnect between policy and realistic application.

"OPWDD didn't care about how you were doing it (following guidance), they just wanted to be sure you were doing it."
- Provider

Providers also said their efforts to get technical assistance for implementation of guidance from OPWDD, for the most part, went unanswered. In focus groups, provider organizations expressed disappointment in OPWDD's response, particularly when seeking guidance in obtaining PPE. OPWDD noted that OPWDD's Regional Offices created on-call systems, available 24 hours a day, seven days a week, to provide technical assistance to providers; however, this was not mentioned in any provider focus groups.

"With directives coming from OPWDD, DOH and the CDC, it was not clear who was the lead." – Provider

Classification of Group Homes

Both providers and family members expressed concern that regulations and guidance issued by the state were not clear on whether OPWDD licensed group homes and family care residences were categorized similarly to nursing homes. Providers reported, in some cases group homes were classified in the same category as nursing homes, and in some cases, they were not, which led to confusion and frustration. While the state acknowledged the susceptibility of people with IDD and staff in congregate settings to COVID-19 through various guidance, New York did not place the same level of priority for the distribution of PPE to providers as they did for nursing homes.[19] Providers were directed to acquire PPE through their local emergency management office, while nursing homes were prioritized for state PPE distribution by DOH.

"There was a general misunderstanding we are not a nursing home or a medical facility that has oxygen or 24-hour care."
- Provider

In addition, policy issued by the state required staff working in nursing homes to submit to regular COVID-19 testing but did not require DSPs working in group homes to do the same. OPWDD did arrange testing opportunities for symptomatic staff in congregate settings but did not do the same for staff serving people with IDD in the community.

In contrast, providers reported during focus groups they were expected to operate as a nursing home or medical facility and accept residents returning from hospitalization who were asymptomatic but still might be contagious.

DDPC met with staff from DOH on behalf of the DDAC to inquire about the classification of group homes. DOH acknowledged the definition of group homes varied depending on the guidance and

[19] Ibid.

was not always clear and agreed state agencies should collaborate to clarify the classification of group homes and any future related guidance.

PPE

At the start of the pandemic, when PPE supplies were scarce, OPWDD directed voluntary providers to make PPE requests to their local emergency management offices. According to feedback received at the provider focus groups, those requests frequently went unanswered, and there was little to no follow up from the state to ascertain if local emergency management offices were indeed responding to provider requests for PPE. During one focus group, a provider shared they reached out to their local emergency management office, as instructed by OPWDD, and not only were they not on the list of prioritized organizations for PPE distribution, but the local emergency management office had never heard of the organization. Another provider shared a story of a desperate call to a local Emergency Medical Technician (EMT) to try and get PPE. The EMT went down the list of groups who were prioritized to receive PPE, and the provider noticed there was not a single IDD congregate setting on the list. In the rare instances when providers or CCOs were able to obtain PPE through OPWDD or their local emergency management offices, some providers questioned the quality or the appropriateness of the PPE, especially masks, as it did not match the guidance that was issued by the state at that time.

"Providers spent over $16 million on Personal Protective Equipment (PPE) to ensure the safety of their staff and the people they care for, all without any financial support from the State."

- Michael Seereiter, NY Alliance COO in testimony to state legislature

Providers shared during focus groups they relied on their own resources to acquire PPE or on their member associations to broker PPE purchases and distribute on their behalf. While providers were ultimately reimbursed for the costs of obtaining PPE when Federal American Rescue Plan Act funds became available, there were many months of fiscal uncertainty.

Smaller organizations and organizations in underserved communities with less purchasing power talked about their struggles with purchasing and acquiring PPE. These organizations expressed disappointment in the OPWDD response when seeking guidance for obtaining PPE. Providers felt that as OPWDD staff shifted to remote work during early phases of COVID-19, there were often delays or disruption in communications between OPWDD and community-based organizations, requiring community-providers to devote additional time and resources to locating PPE.

According to providers, the state's PPE distribution plan potentially impacted the health and safety of the residents and staff in provider-operated facilities and was initially an extreme financial burden for providers. It should be noted that one dually OPWDD/Office of Mental Health (OMH)

licensed provider from New York City shared they were able to get PPE directly from OMH but, in contrast, were directed by OPWDD to reach out to their local emergency management office.

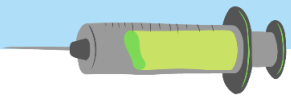
"We were entering into the shark tank in terms of procuring PPE. We did a lot of outsourcing and spent a lot of money because we were not in the state pipeline." – Provider

While accessing PPE was the most common issue raised in provider focus groups, some agencies did mention that OPWDD provided a way for them to report PPE shortages so OPWDD could relay this information directly to emergency management offices. This did lead to some providers getting assistance with PPE early on in the pandemic.

Vaccination Guidelines

According to data provided by OPWDD, with 98.7% of programs reporting, only 27.3% of direct care staff were either fully or partially vaccinated as of April 2, 2021. This pales in comparison to the 79.9% of residents fully or partially vaccinated by April 2, 2021. In addition, the staff declination rate was nearly two times higher than residents. Anecdotally, providers shared while they would support more staff getting vaccinated, they are unable to enforce vaccine requirements because they cannot afford to lose additional staff due to staffing shortages, and they do not have additional funds to provide financial vaccination incentives. One provider shared they mandated vaccination for their workforce and lost 6% of their DSPs as a result.

Only 27.3% of staff in certified residences were either fully or partially vaccinated, compared to residents, who were vaccinated at a rate of 79.9%



Quarantine Policies

In focus groups, providers shared multiple challenges in following the state-issued quarantine guidance. In some cases, the size of the facility/home or the layout of the building made it nearly impossible to be compliant. One provider shared while OPWDD was re-purposing buildings to serve as quarantine overflow for residents in OPWDD operated facilities, these facilities were not made available to struggling providers in the community.

Enforcement of quarantine for some people with IDD was challenging due to complex behavioral needs.

Providers in focus groups suggested flexibility with the implementation of quarantine and staffing guidance to accommodate these changes would have been helpful. Providers also indicated they were not always able, physically or financially, to meet these restrictions. Providers also shared, by the time quarantine guidance was issued by the state, they had already set up a quarantine system on their own to minimize transmission. They further

described the process to get approval from the state to re-purpose facilities for quarantining as prohibitively time-consuming.

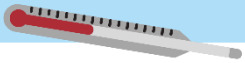
Enforcement of quarantine guidance for some people with IDD with complex behavioral needs was particularly challenging for providers. DSP shortages was most frequently cited by providers as the most significant barrier to quarantine guidance compliance. They just did not have enough staff to spread out and still adequately meet the needs of the people they were serving.

Hospitalization Discharge Policy

"Hospital discharges are the classic example of what was wrong in the first year of the pandemic. There was an active push for us to take our people back unless we created our own spine." - Provider

Providers in focus groups shared great concern with the policy requiring them to accept asymptomatic people with IDD back into the residences upon discharge from the hospital, regardless of suspected COVID-19 status. Although there was an acknowledgement this policy was intended to open hospital beds for more people infected with COVID-19, providers said accepting people with IDD discharged from the hospital back into the residence created major safety and operational implications.

One administrator recalled receiving a call out of the blue from the hospital, telling them to pick their resident up. When they arrived, the client had already been discharged, but was discovered by staff to have a fever of 103 degrees.



"Our medical directors had to continually make the case to not return residents we could not care for and educate hospitals on who we are and what our facilities look like." -Provider

Some providers did share that OPWDD paved the way for people to be discharged to temporary repurposed IDD facilities (for example day program sites, respite program sites) that were set up to care for people who were still positive. OPWDD also allowed providers flexibility in billing for this service. This protected people from returning to homes and infecting others and minimized hospital stays.

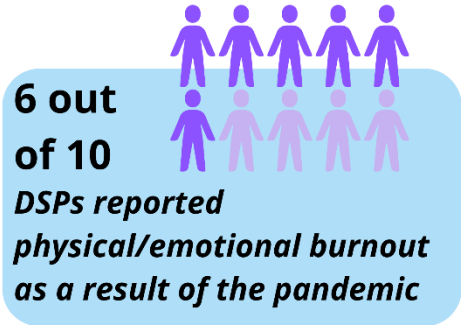
DSP Workforce Crisis

The pandemic further stressed a workforce already in crisis. This crisis might more accurately be described as a long-term chronic shortage of people willing to perform the arduous work of a DSP at the pay and conditions offered. This shortage is not unique to New York and has steadily and predictably become more acute over the last two decades.

According to a survey conducted in 2021 by the New York Disability Advocates, one in four DSP positions are currently vacant in New York.[20] This represents an approximate 75% increase from

[20] New York Disability Advocates. (2021). 2021 NYDA Workforce survey.

the average vacancy rate before the pandemic.[21] Further compounding the situation is a lack of applicants for the many vacant positions, with 93% of agencies reporting a decrease in job applicants.[22] Rural areas of the state are especially hard hit with people with IDD being placed in new group homes or facilities, sometimes further away from their families, due to the suspension of services from staffing shortages.[23]



According to a survey by the National Association of Direct Service Providers, the mass exodus of DSPs in New York can be attributed to many factors such as increased length of shifts, change in job expectations, physical/emotional burnout, lack of supports like child-care and low pay.[24]

During focus groups, providers shared that chronic staffing shortages were only intensified by COVID-19. It was difficult to incentivize people to keep working while their health, and thereby health of their families, was at risk. They also shared there just wasn't enough staff to properly implement most staffing guidance issued by the state, and OPWDD did not fully recognize these challenges. One provider said, "there just weren't enough bodies to work."

Recognizing the pandemic exacerbated the DSP staffing crisis, OPWDD informed providers they could use their staff (Care managers, community habilitation staff, etc.) to deliver food, prescriptions, etc. and bill for this service. Stakeholders in all focus groups felt it was the DSP workforce that continued to be the backbone of service delivery during the pandemic.

"It's been the extraordinary efforts of DSPs that have made the most profound difference in people's lives throughout the pandemic, often at a great cost to their families and to themselves." [NY Alliance testimony]

Appendix K and Other Waivers

In focus groups, providers expressed appreciation for the financial and operational flexibilities afforded by the implementation of Appendix K and other waivers. These flexibilities included the ability to bill for services such as telehealth; reducing required staff training; increasing fees for respite and community habilitation services; and reducing requirements for incident reporting and service duration minimums.

However, some providers did express concern that OPWDD took too long in its negotiations with the Federal Center for Medicaid Services (CMS) for approval of amendments to Appendix K and

[21] Ibid.
[22] Ibid.
[23] Lyons, B. (2022, August 1). Staffing shortages continue to spur group home closures. *Times Union.* www.timesunion.com
[24] National Alliance for Direct Support Professionals. (2021). Providing support during the COVID-19 pandemic: Direct Support Workforce 12-month follow-up survey - New York version. www.nadsp.org

other waivers. The first case of the virus in New York was identified on March 1, 2020, and the closure of day programs was announced on March 17, 2020; however, it took until April 20, 2020, for the amendments to the Appendix K waiver to be made effective.

Providers also strongly advocated exploring how the state could make these flexibilities permanent, as most providers reported finding successes with operating under this alternate framework.

Data Collection and Distribution

As reported by OPWDD, the Incident Report and Management Application (IRMA) was used to collect COVID-19 cases and fatalities from providers and state operated settings. IRMA is a data management system that was utilized by OPWDD prior to the pandemic and was designed to track all incidents, including restraints of residents, in one central location. OPWDD shared they had to quickly modify this system to be able to track COVID-19-related data used to inform guidance-related decisions. According to OPWDD, the data collected from IRMA could not be compared to data collected by DOH on the general population, since the data definitions used by OPWDD were not compatible with DOH data definitions. Both providers and parents in focus groups noted the limitations in the data prevented OPWDD from identifying trends and taking appropriate response measures.

During focus groups, providers frequently said that entering COVID-19 related data daily, at the height of the pandemic, was extremely burdensome and took time away from serving people with IDD. OPWDD noted that assistance was provided with data entry upon request and many providers accepted assistance; however, this was not mentioned in any provider focus groups. In addition, they reported OPWDD did not initially share COVID-19-related data during stakeholder calls, and it was only after repeated requests from stakeholders that it was added to the agenda. Providers, self-advocates and other stakeholder groups also mentioned data was initially reviewed verbally during these calls and when it was shared in a visual format, was not user-friendly or very informative.

Better data collection and information sharing was discussed in a focus group of Long Island and NYC area agency providers. One provider shared, “we quickly realized people with Down Syndrome were much more adversely affected…If other agencies upstate were informed, where the explosion of cases didn’t happen for many months, they could have been prepared…Sharing that knowledge could have made a difference in a response and in people’s lives.” The group also shared that many provider groups in the Long Island and NYC area coordinated weekly calls to discuss trends and other timely information but acknowledged it should have been OPWDD coordinating those regional calls in order to understand and collect important information to share.

Recommendations

"Not only were we the last group thought about, we were never spoken of." – Family member

The DDAC strongly urges Governor Hochul and the NYS Legislature to consider the following recommendations to better prepare New York to meet the needs of people with IDD during any future public emergency.

RECOMMENDATION: Create an Emergency Management Plan Specifically for the IDD Community

New York State does have an Emergency Management Plan that provides all-hazard guidance during an emergency; however, the plan is general in nature and does not specifically address the special needs of the diverse IDD community in New York. The DDAC strongly recommends OPWDD develop an emergency management plan, specifically designed for the IDD community to anticipate, and thereby, mitigate some of the specific crisis situations experienced during the COVID-19 pandemic. The plan should be created with input from the IDD Community and include, at a minimum, the following items:

- ***Include the IDD Community in the COVID-19 Review RFP Issued on July 20, 2022***
  On July 20, 2022, Governor Hochul issued a Request for Proposal (RFP) for an independent consultant firm to provide an "after action review" of the state's COVID-19 response, identify what worked and what did not, and recommend how the state could have improved its response. Additionally, the RFP calls for the review to be used as "a guide for New York State and for other governments to use in order to respond quickly and effectively to significant emergencies, whether they are pandemics, natural disasters or other emergency conditions that create major disruptions to normal life."
    - To understand the full impact of the pandemic on ALL New Yorkers and integrate an all-encompassing improved response in the future, the DDAC strongly recommends this RFP and future guide include a comprehensive review of the response to the IDD community, what could have been improved and a plan for the future.

- ***Improve and coordinate communication***
    - Make guidance issued understandable and accessible, especially for people with IDD and New Yorkers for whom English is a second language. Some suggestions from focus groups include brief flyers with graphics and plain language, plain language documents translated into other languages, and culturally accessible communication platforms such as ethnic radio.

- Ensure Emergency Management Planning is informed by voices that represent the racial, ethnic, and linguistic diversity of New York State, including multicultural providers.

- Partner with community-based organizations, especially those in underserved communities, and leverage existing agency partners to assist in the distribution of information.

- Create a centralized hotline or point of contact office to answer questions from stakeholders, including implementation-related questions from providers and staff at OPWDD-certified facilities.

- Provide guidance in a timely manner. Give guidance to providers in advance of its release to the public to provide an opportunity for providers to ask clarifying questions and implement the guidance accordingly.

- ***Include considerations for the IDD Community***
  - Support and coordinate statewide special accommodations for vaccination, testing, distribution of PPE, or any other relevant emergency measures for people with IDD, their family members and DSPs. Examples include special hours of operation at testing and vaccination sites for people with IDD, family caregivers and DSPs; and state-level coordination for the distribution of PPE for people with IDD living in the community and community-based providers.

  - Examine the efficacy of visitation policies in each setting related to the IDD community, specifically when it makes most sense to restrict or relax guidance.

  - DOH and OPWDD should work together to modify hospital discharge policies for people with IDD, taking into consideration unique factors such as residential setting and caregiver status.

  - Formalize and communicate exceptions for people with IDD who are unable to comply with guidance. For example, making exceptions for an individual with IDD with complex behavioral needs who refuses to wear a mask but needs medical care.

  - Provide minimum standards and best practices to providers, enabling them to adjust to the many different needs of a particular setting or the people they serve while maintaining a standard level of safety. If providers have barriers to meeting standards outlined in safety guidance, OPWDD and the provider should work collaboratively to problem solve, while optimizing safety.

- ***Minimize disruption of services***
  OPWDD should consider the unique needs of sub-groups within the IDD population when developing a plan to minimize disruption of services. Examples of unique needs include, but are not limited to, medical fragility, complex behavioral needs, being homebound and the ability of caregivers to provide supports.

    - Create a system to prioritize for day program services when it is deemed safe to do so, considering factors as the person with IDD's ability to participate in virtual programming, the caregivers' circumstances and access to reliable internet and electronic devices.

    - Make telehealth, telemedicine and virtual programming permanent, ongoing services when it is appropriate for an individual with IDD. Develop and distribute best practices on delivering these services for providers.

    - Provide formal communication channels to connect family members with support groups when respite services are unavailable, or when family members need support in general.

    - Include the needs of people with IDD living in the community when issuing statewide guidance or provide separate guidance specifically for people with IDD in the community

- ***Coordinate with local emergency management offices to educate and establish protocols on the needs of the IDD community so EMOs are adequately prepared to assist people with IDD, family caregivers and providers during a public emergency.***

- ***Require mandatory training for all first responders to be able to understand and respond appropriately to the unique needs of people with IDD.***

- ***Streamline data collection and improve accessibility during an emergency.***
    - Create an OPWDD data management system that is consistent with DOH data measures, user friendly and less burdensome for providers.

    - Produce an interactive emergency data dashboard that is searchable and user-friendly for the public. The dashboard should be in an accessible format and easily located on the OPWDD website.

RECOMMENDATION: Address Systemic Issues Exacerbated by the Pandemic

The state attempted to maintain a system of service delivery during the pandemic as much as circumstances would allow; however, the pandemic highlighted, if not exacerbated, the need to address long-standing systemic issues.

- ***Improve coordination between NYS agencies and local government offices during a public emergency.***
    - Conduct a holistic review of all COVID-19 response related reports that have been released thus far.

    - DOH and OPWDD should work collaboratively to determine how to classify OPWDD-licensed group homes and family care residences, and clarify how regulations, guidance and mandates apply to those types of facilities – especially during an emergency.

    - Distribute any IDD-guidance issued during an emergency directly to local emergency management offices.

    - Require a listing of community-based providers for all local emergency management offices.

- ***Address the chronic DSP workforce crisis***
    - Create a DSP workforce taskforce, comprised of representatives from OPWDD, providers, DSPs and other stakeholders to develop recommendations to alleviate the crisis, including but not limited to strategies to retain and recruit workers; address low wages and pay disparities; and professionalization of the field**.**

- ***Reduce reliance on congregate care***
  People with IDD living in certified settings were particularly hard hit by the pandemic and the current administrative, fiscal and regulatory structures in New York State favors OPWDD certified settings rather than independent housing with supports for people with IDD.
    - As a first step, the state should convene a workgroup of stakeholders to examine current regulatory, financial, and administrative barriers to offering more independent housing options for people with IDD and make recommendations to change the current housing system to provide people with IDD more person-centered choices.

- ***Maintain and Expand Flexibilities***
    - Study the flexibilities afforded to providers through various emergency Executive Orders and Appendix K waivers to determine the impact and feasibility of continuing such flexibilities permanently.

    - Provide flexibility for people who self-direct to be able to hire necessary staff without having to make changes to their budget, which can take months to approve.

- ***Address the Digital Divide for People with IDD***
    - Expand OPWDD programming to implement strategies focused on digital equity for people with IDD so they have the opportunity to be fully engaged digital citizens.

    - Create a system of information distribution for times of emergency that can reach people with IDD and their caregivers without requiring the use of digital technology, such as the utilization of ethnic radio or partnerships with community organizations.

    - Consider the use of alternative forms of digital communications – many individuals with IDD do not have a computer but do make use of social media through smart phones and tablets.

    - Connect IDD agencies, like OPWDD and DOH, to the NYS Digital Equity Workgroup to increase their efforts to serve people with IDD, especially those living in underserved or rural communities.

- ***Collaborate with Trusted Partners to Reach Underserved Communities***
    - Partner with community-based organizations (CBOs), multicultural providers, and other trusted community leaders to ensure successful outreach to underserved communities.

    - Translate vital information into the top twelve languages spoken in New York State and distribute via trusted messengers or culturally accessible communication platforms.

- ***Promote mental wellness of people with IDD, family caregivers and the workforce***
    - OPWDD should promote awareness of the signs and symptoms of behavioral health concerns, provide tools to guide difficult conversations, and promote availability of training and resources e.g., OMH webinars, Mental Health First Aid, Adverse Childhood Experiences (ACEs), trauma informed practices, Stages of Change.

Additional Areas of Concern

During the process of analyzing and gathering stakeholder feedback, the DDAC identified several additional areas of concern outside of the scope of the COVID-19 report legislation. The DDAC urges Governor Hochul and the Legislature to further consider the following:

- Some stakeholders shared that people with IDD continue to have difficulties accessing health, dental, behavioral, and mental health service due to the lack of Medicaid providers. It is difficult to find providers who serve people with IDD and are knowledgeable about their needs. This issue was even more apparent during the pandemic.

- Family caregivers were often the only support for their loved ones with IDD during the pandemic; however, many expressed during focus groups they felt undervalued by New York State. How much unpaid care did family caregivers provide during the pandemic which allowed loved ones to stay home, return home (reducing stress on agency provided supports) or avoid crisis placements and hospitalizations? How can New York provide more supports to these family members?

- What impact, if any, does a public emergency have on the safety of residents or possible incidents of abuse in congregate settings? What can be done to ensure the safety of the residents?

- Was there an increase in the prescription of anti-psychotic medications for people in congregate settings during the pandemic? Several family members shared during focus groups that their loved ones were unnecessarily prescribed medications that "made them vegetables" to make them "easier to deal with." Reduced, changing, and inexperienced staff were some of the contributing factors noted by parents.

- During the initial days of the pandemic, the IDD service delivery system was essentially shut down. People with IDD and families attempted to gain initial access during this time but received little to no response or faced massive delays in the enrollment process. How can the state ensure that people with IDD and their families, either new to the system or existing recipients, can still gain access to services during a long-term emergency? The needs of people with IDD and families remain just as acute during a pandemic or any other emergency.

- Are there human rights issues related to placing more restrictive measures for people with IDD that are not required for the general public? For example, should people with IDD be required to wear a mask while using provider transportation while the general public does not have to wear a mask on a public bus? Should people with IDD living in a group home in

the community be prevented from participating in activities in their community when the general public does not have the same restrictions? What guidance is safe, as well as fair, for people with IDD and the public at large?

- Can New York leverage the newly formed Office of the Chief Disability Officer to coordinate effective public emergency planning for people with IDD, including serving as a liaison between state agencies such as DOH, OPWDD, OMH and local emergency management offices; self-advocates; providers; family caregivers and organizations representing stakeholders?

- Written reports and testimony about the effects of the pandemic make it clear that one of the most vulnerable groups are the infirm elderly. The older generation of people with IDD, some of whom are survivors of institutional care, tend to live in larger more congregate settings. The type of residence, with attendant turnover of DSPs and lack of options for quarantine, contributed to the deaths of people with IDD. How can OPWDD collaborate with the Office of the Aging, OMH and the New York State Office of Addiction Services and Supports to better understand how to support an aging population that may have severe and chronic health conditions? This would include a reexamination of the congregate shift-based model, with an eye to safer, healthier ways to provide a home.

Conclusion

The COVID-19 pandemic illustrated a host of vulnerabilities in New York State, but more so for people with IDD. As studies noted, having an intellectual or developmental disability is "the strongest independent risk factor" for COVID-19 diagnosis or mortality. COVID-19 deaths were anywhere from one and a half to more than two times higher for people with IDD than the general population. Even within the IDD community, people living in group homes were four times more likely to test positive and two times more likely to die as compared to people with IDD living in other settings.

While there was no pandemic or other emergency plan in place that could have smoothly navigated the early stages of the pandemic, guidance that was developed reactive to the event often lagged and did not address the unique needs of the IDD population, families, or providers in a responsive manner.

The impact of the state's response permeated far beyond people with IDD, who experienced increased isolation, regression, and mental health and behavioral issues. It profoundly impacted family caregivers who reported feeling overwhelmed and without support, and providers who scrambled to find ways to make information understandable and accessible, while keeping staffing and health and safety a priority.

No doubt March 2020 through April 2021 was an extraordinary and unforeseen time for our state, nation and the entire globe. However, we now have a unique opportunity to look back on that first year, outside of the critical day-to-day emergent issues, and examine some of the long-standing systemic issues exacerbated by the pandemic and identify creative solutions. We ask the Legislature and the Governor to consider this monumentally difficult time in New York State history as an occasion to rethink the delivery of IDD programs and services in our state, not only to be more planful and proactive in the event of another public emergency, but in its duty to serve all of New York's citizens.

Appendix A – Report Legislation

STATE OF NEW YORK

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6294--A

Cal. No. 1025

2021-2022 Regular Sessions

IN SENATE

April 20, 2021

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Introduced by Sen. MANNION -- read twice and ordered printed, and when printed to be committed to the Committee on Disabilities – reported favorably from said committee and committed to the Committee on Finance -- reported favorably from said committee, ordered to first and second report, ordered to a third reading, amended and ordered reprinted, retaining its place in the order of third reading.

AN ACT to amend the mental hygiene law, in relation to requiring the developmental disabilities advisory council to produce a report evaluating the state's response to the COVID-19 state disaster emergency as it relates to individuals with intellectual or developmental disabilities; and providing for the repeal of such provisions upon the expiration thereof.

The People of the State of New York, represented in Senate and Assembly, do enact as follows:
Section 1. Section 13.05 of the mental hygiene law is amended by adding a new subdivision (g) to read as follows:

(g) The developmental disabilities advisory council shall produce a report to review the impact and the state's response to the COVID-19 state disaster emergency, as declared by executive order two hundred two of two thousand twenty, as it relates to individuals with intellectual or developmental disabilities. The office and the department of health shall provide technical assistance and access to data as is required for the council to effectuate such review and produce such report. The report shall include, but not be limited to:

(i) a timeline and inventory of any and all relevant executive orders, guidance and regulations put forth by the department of health, the office, the executive or any other agency between March first, two thousand twenty and April first, two thousand twenty-one in response to the COVID-19 outbreak;

(ii) a timeline of any outreach conducted by the office with stakeholders, including self-advocates, family advocates and voluntary providers and what, if any, changes to guidance were made as a result of such communication with stakeholders;

(iii) any actions or guidance the office, the department of health and/or any other agency took to minimize exposure of COVID-19 between residents and staff;

(iv) an inventory of actions the office, the department of health and/or any other agency took to assist in the procurement or provisioning of personal protective equipment for residents and staff in state operated facilities, and facilities operated by voluntary providers. For purposes of this section, "personal protective equipment" shall mean all equipment worn or used to minimize exposure to a communicable disease, including but not limited to gloves, masks and face shields;

(v) an inventory of costs incurred by the office related to responding to COVID-19;

(vi) an inventory of actions the office, the department of health and/or any other agency took to assist underserved communities including but not limited to racial and ethnic minority communities; and

(vii) specific challenges that were faced with regards to individuals with intellectual and developmental disabilities.

(2) The developmental disabilities advisory council shall also evaluate policies, procedures, and programs that were implemented during the course of the COVID-19 pandemic to determine the efficacy on safety.

(3) The developmental disabilities advisory council shall provide recommendations of changes to any laws or regulations that impeded response to COVID-19 to the legislature.

(4) Such report shall be submitted to the governor, the temporary president of the senate and the speaker of the assembly no later than nine months from the effective date of this subdivision and shall be made publicly available online.

§ 2. This act shall take effect immediately and shall expire and be deemed repealed ten days after transmission of the report of the findings by the developmental disabilities advisory council to the governor, the temporary president of the senate and the speaker of the assembly,

34 as provided in section one of this act. Provided, however, that the commissioner of the office for people with developmental disabilities shall notify the legislative bill drafting commission upon the transmission of the report of the findings of the office for people with developmental disabilities, as provided in section one of this act, in order that the commission may maintain an accurate and timely effective data base of the official text of the laws of the state of New York in furtherance of effectuating the provisions of section 44 of the legislative law and section 70-b of the public officers law.

Appendix B – Timeline of State-Issued Guidance Related to People with IDD from March 1, 2020 to April 1, 2021

Date	Agency	Title	Minimizes Exposure between Staff & Residents
3/10/2020	OPWDD	Visitor Guidance	X
3/11/2020	OPWDD	OPWDD Guidelines for Implementation of Quarantine and/or Isolation Measures at State Owned and Voluntary Providers in Congregate Settings	X
3/12/2020	Exec. Chamber	Executive Order 202.1	X
3/13/2020	OPWDD	Employee Guidance	
3/13/2020	OPWDD	Site Visit Guidance	X
3/14/2020	DOH	Face to Face Requirements Waived for Health Home Care Management, Unless Medically Necessary	
3/17/2020	OPWDD	Immediate Temporary Suspension of Day Program Services	X
3/17/2020	OPWDD	Covid-19 Phone Notification Requirements for OPWDD Providers	
3/18/2020	DOH	Health Advisory: COVID-19 Guidance for Hospital Operators Regarding Visitation	
3/18/2020	Exec. Chamber	Executive Order 202.5	X
3/18/2020	OPWDD	COVID-19 Guidance for IRA's and Community Residences	X
3/18/2020		DSP's Essential Workers	X
3/19/2020	OPWDD	Interim Guidance for Community Habilitation Services Regarding COVID-19	X
3/20/2020	OPWDD	COVID-19 Guidance for Providers on Essential Businesses	X
3/24/2020	OPWDD	Management of Coronavirus/COVID-19 in OPWDD Family Care Homes	X
3/24/2020	OPWDD	COVID-19 Suspension of Community Outings and Home Visits	X
3/25/2020	OPWDD	Article 16 Clinic Management of Coronavirus	X
3/25/2020	OPWDD	Health Advisory: Respiratory Illness in Intermediate Care Facilities for Individuals with I/DD	X
3/25/2020	OPWDD	Care Management Guidance	
3/25/2020	OPWDD	Staff Guidance for the Management of Coronavirus (COVID-19) in Facilities or Programs Certified by OPWDD	X
3/27/2020	Exec. Chamber	Executive Order 202.11	X
3/27/2020		Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation	X
3/28/2020	DOH	Medicaid Changes to Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS) Policy	

3/28/2020	OPWDD	COVID-19 Protocols for Direct Care Staff to Return to Work	X
3/28/2020	OPWDD	Release from quarantine guidance	X
3/29/2020	DOH	COVID-19 Guidance regarding 1915(c) HCBS Children's Waiver for Children's Health Homes and Children, Youth Evaluation Services (C-YES), HCBS Providers, and MMCP/HIV SNP	X
3/30/2020	Exec. Chamber	Executive Order 202.13	
3/30/2020	OPWDD	Temporary Emergency Respite	
4/2/2020	DOH	Options when Personal Protective Equipment (PPE) is in Short Supply or Not Available	X
4/4/2020	DOH	Guidance for Resident and Family Communication in Adult Care Facilities and Nursing Homes	X
4/7/2020	Exec. Chamber	Executive Order 202.14	
4/7/2020		Letter approving Appendix K Waiver	
4/9/2020	OPWDD	COVID-19 Respirator and Facemask Use for Direct Care	X
4/10/2020	DOH	Health Advisory: COVID-19 Updated Guidance for Hospitals Regarding Visitation	
4/10/2020	OPWDD	Interim Guidance Regarding Modified Background Check Requirements for Existing and New Staff Members of OPWDD Operated and Certified Providers During COVID-19 Emergency	
4/10/2020	OPWDD	Advisory: Hospital Discharges and Admissions to Certified Residential Facilities	X
4/10/2020	OPWDD	COVID-19 Guidance for the Management of Intravenous Therapy in OPWDD residences	X
4/10/2020	OPWDD	Performing Nursing Services Remotely in Residential Settings	
4/10/2020	OPWDD	Interim Guidance Regarding the Use of Telehealth/Covid-19	X
4/12/2020	Exec. Chamber	Executive Order 202.16	
4/17/2020	OPWDD	Interim Guidance Regarding Care Planning Activities	
4/17/2020	OPWDD	Interim COVID-19 Guidance Regarding Community Habilitation	X
4/24/2020	OPWDD	Extension of Interim Billing Guidance for Providers of Day Habilitation, Prevocational and Day Treatment Services Regarding Emergency Response to COVID-19 through April 15, 2020	
4/24/2020	OPWDD	Interim COVID-19 Guidance Regarding Community Habilitation	
4/24/2020	OPWDD	Interim COVID-19 Guidance Regarding Prevocational Services	
4/24/2020	OPWDD	Interim COVID-19 Guidance Regarding Day Habilitation	X

4/26/2020	DOH	Updated Interim Guidance: Protocol for COVID-19 Testing Applicable to All Health Care Providers and Local Health Departments	X
4/28/2020	DOH	Revised Staff Guidance for the Management of Coronavirus (COVID-19) in Facilities or Programs Operated by OPWDD	X
5/10/2020	Exec. Chamber	Executive Order 202.30	
5/18/2020	OPWDD	COVID-19 Risk Stratified Enhanced Oversight	
6/5/2020	Exec. Chamber	Executive Order 202.38	
6/5/2020	OPWDD	COVID-19 REVISED Protocols for Direct Care Staff to Return to Work	X
6/6/2020	Exec. Chamber	Executive Order 202.38	X
6/18/2020	OPWDD	COVID-19: Interim Visitation Guidance for Certified Residential Facilities	X
7/10/2020	OPWDD	Reintroduction of Individuals to Certified Residences After Extended Home Visits	X
7/10/2020	OPWDD	Interim Guidance Regarding Reopening of Day Services	
7/10/2020	OPWDD	COVID-19 Interim Guidance on Home Visits	X
7/10/2020	OPWDD	Interim Guidance Regarding Community Outings for Individuals Residing in OPWDD Certified Residential Facilities	X
7/16/2020	OPWDD	Interim Guidance Regarding Reopening of Day Services REVISED	
8/17/2020	OPWDD	COVID-19 Interim Guidance Regarding Community Outings REVISED	X
8/18/2020	OPWDD	Interim Guidance Regarding In-Person Services at Article 16 Clinics	X
8/21/2020	OPWDD	Local Assistance Payment Withhold	
8/24/2020	OPWDD	Interim Post Day Service Retainer Program Guidance	
9/2/2020	OPWDD	Interim COVID-19 Guidance Regarding Community Habilitation REVISED	
9/3/2020	OPWDD	Interim COVID-19 Guidance Regarding Prevocational Services REVISED	
9/3/2020	OPWDD	Interim COVID-19 Guidance Regarding Respite	
9/3/2020	OPWDD	Interim COVID-19 Guidance Regarding Day Habilitation REVISED	
9/3/2020	OPWDD	Interim COVID-19 Guidance Regarding Supported Employment	
9/3/2020	OPWDD	Interim COVID-19 Guidance Regarding Pathway to Employment	
9/15/2020	OPWDD	COVID-19: Interim Guidance for Non-Emergency Site Visits of Verified Facilities	X
9/18/2020	OPWDD	Interim Guidance Regarding Care Planning Activities REVISION	

9/18/2020	OPWDD	Interim Billing Guidance Regarding Intermediate Care Facility Day Services effective 7/22/20 through 10/14/20	
10/20/2020	OPWDD	Management of Co-Circulation of Influenza and Covid-19	X
10/23/2020	DOH	Health Advisory: All Residential Congregate Facilities	X
10/23/2020	OPWDD	Interim COVID-19 Guidance: Designated Cluster Mitigation	X
10/28/2020	OPWDD	COVID-19: Interim Visitation Guidance for Supportive Residential Facilities	X
11/10/2020	OPWDD	COVID-19 2nd REVISED Protocols for Direct Care Staff to Return to Work	X
11/16/2020	OPWDD	COVID-19 3rd REVISED Protocols for Direct Care Staff to Return to Work	X
12/20/2020	DOH	Guidance for the NYS Office for People with Developmental Disabilities (OPWDD), Office of Mental Health (OMH), and Office of Addiction Services and Support (OASAS) Prioritization of Essential Healthcare and Direct Support Personnel as well as High Risk Populations for COVID-19 Vaccination	X
12/22/2020	OPWDD	Interim COVID-19 Memorandum: COVID-19 Vaccine Prioritization in Certain OPWDD Certified Residential Settings	X
12/30/2020	OPWDD	Interim Guidance: Use of an Informed Consent Committee for Consent to the COVID-19 Vaccine	
1/5/2021	OPWDD	Interim COVID-19 Guidance: Week 4 COVID-19 Vaccine Prioritization in OPWDD Certified Settings	X
1/14/2021	OPWDD	Interim COVID-19 Guidance: Week 4 COVID-19 Vaccine Prioritization in OPWDD Certified Settings REVISED	X
1/22/2021	OPWDD	COVID-19 4th REVISED Protocols for Direct Care Staff to Return to Work	X
2/24/2021	OPWDD	Local Assistance Payment Withhold – Update	
2/28/2021	DOH	Guidance for the New York State COVID-19 Vaccination Program	
3/15/2021	OPWDD	COVID-19: Interim Visitation Guidance for Certified Residential Facilities REVISED	X
3/30/2021	OPWDD	Updated Interim Guidance Regarding Reopening of Day Services REVISION	
3/30/2021	OPWDD	COVID-19 5th REVISED Protocols for Direct Care Staff to Return to Work	X
3/30/2021	OPWDD	COVID-19: Interim Visitation Guidance for Certified Residential Facilities 2nd REVISION	X

Appendix C – Timeline of State-Issued Communication Related to People with IDD from March 1, 2020 to April 1, 2021

Date	Activity	Topic
3/12/2020	Email	Guidelines for required reporting to OPWDD when an individual is confirmed for quarantine and/or isolation from COVID-19.
3/13/2020	Stakeholder Meeting	
3/14/2020	Email	Additional COVID-19 "Coronavirus" Guidance and Entry into IRMA
3/15/2020	Stakeholder Meeting	
3/17/2020	Email	IMPORTANT-DAY SERVICES INFORMATION -- day program closure memo
3/17/2020	Email	IMPORTANT Covid-19 Reporting Guidance Documents -- phone reporting directions to field
3/17/2020	Stakeholder Meeting	
3/19/2020	Email	Guidance from OPWDD-Guidance IRAs, CRs, and Private Schools and Coronavirus no visitors poster -- 3.18.20 visitation guidance
3/19/2020	Email	REVISED: COVID-19 Reporting Guidance document_03/19/2020
3/19/2020	Email	NEWLY REVISED: COVID-19 Reporting Guidance document_03/19/2020 -- Phone reporting directions to field
3/19/2020	Email	UPDATE to IMPORTANT-DAY SERVICES INFORMATION -- Day Program provider notification emergency response template
3/19/2020	Stakeholder Meeting	
3/21/2020	Stakeholder Meeting	Status of Appendix K & Other Waivers
3/23/2020	Email	Provider Webinar - COVID Response Overview -- Registration for 3/23 @1pm and 3/24@2pm
3/23/2020	Email	Provider Temporary Site Capacity Survey
3/23/2020	Stakeholder Meeting	
3/25/2020	Stakeholder Meeting	
3/26/2020	Email	REVISED EMERGENCY RESPONSE TEMPLATES, Provider notification of emergency response template
3/30/2020	Email	Temporary Emergency Respite Capacity in Response to COVID-19 -- Temp covid emergency respite opportunity
3/30/2020	Stakeholder Meeting	First OPWDD record of stakeholder meetings
3/31/2020	Email	IRMA TRAINING Registration Information
4/1/2020	Stakeholder Meeting	Discussed criminal background checks
4/3/2020	Email	IRMA presentation given on 04/01/2020 for COVID-19
4/3/2020	Stakeholder Meeting	Appendix K updates and hospital visitation allowed
4/6/2020	Stakeholder Meeting	Hospital visitation discussion
4/8/2020	Stakeholder Meeting	Appendix K approval
4/9/2020	Webinar	Webinar hosted with the Managed Care Community of Practice (MCCOP) on Appendix K and billing guidance

4/10/2020	Email	OPWDD Contact Tracing Operational Instructions -- guideline for containment
4/10/2020	Stakeholder Meeting	Discuss hospital visitation/contact tracing
4/12/2020	Email	OPWDD Interim Guidance Related to Background Checks
4/13/2020	Email	Save the Date: Wednesday April 15 - DOH Guidance for COVID-19 Prevention and Response in OPWDD Facilities
4/13/2020	Email	OPWDD Interim Guidance Related to Background Checks -- resent the 4/12 email
4/13/2020	Stakeholder Meeting	Discuss new guidance, waiver service during school hours, staffing
4/14/2020	Email	COVID-19 Interim Guidance Related to Resident and Family Communication for OPWDD Operated, Certified and Funded Residences
4/15/2020	Stakeholder Meeting	Hospital policies
4/17/2020	Webinar	Webinar hosted with MCCOP on use of telehealth
4/17/2020	Stakeholder Meeting	SDS, triage, family reporting in certified settings
4/20/2020	Stakeholder Meeting	Hydroxychloroquine, accessing testing
4/22/2020	Stakeholder Meeting	Stimulus checks, DOH non-discrimination guidance
4/23/2020	Email	Revised Staff Guidance for the Management of Coronavirus (COVID-19) in Facilities or Programs Operated and/or Certified by the Office for People with Developmental Disabilities" online training available in Statewide Learning Management System
4/24/2020	Stakeholder Meeting	Hardship pay, isolation protocols, PPE for FIs
4/27/2020	Email	DOH Guidance for COVID-19 Prevention and Response in OPWDD Facilities webinar is now available in the Statewide Learning Management System (SLMS)
4/27/2020	Stakeholder Meeting	Programmatic responses in certified settings, self-direction and PPE
4/28/2020	Email	Save the Date: Friday May 1 - Guidance and Updates on COVID-19 Reporting and IRMA Input
4/30/2020	Stakeholder Meeting	Rates update, self-direction, re-opening
5/1/2020	Email	COVID-19 Reporting Guidance from May 1, 2020, Webinar -- new reporting & IRMA entry
5/1/2020	Stakeholder Meeting	Data updates
5/1/2020	Webinar	COVID-19 Reporting and IRMA Input training
5/4/2020	Stakeholder Meeting	Enhanced oversight plan, return to work guidance, cloth face masks
5/7/2020	Stakeholder Meeting	Return to work, testing, communication with individuals, reopening
5/8/2020	Email	Essential Workers COVID-19 testing flyer
5/11/2020	Stakeholder Meeting	Testing, care management questions from SOYAN
5/14/2020	Webinar	Revisions to the retainer program
5/18/2020	Email	COVID-19 Risk Stratified Enhanced Oversight memorandum
5/18/2020	Stakeholder Meeting	Presumptive eligibility, training for individuals, reopening process

5/20/2020	Email	COVID-19 Risk Stratified Enhanced Oversight Review Tools
5/21/2020	Email	DQI COVID-19 Oversight Activities
5/21/2020	Stakeholder Meeting	Data and fiscal meeting
5/22/2020	Webinar	Service Authorization and Care Planning During COVID-19
5/28/2020	Stakeholder Meeting	Self-direction webinar, visitation
5/29/2020	Email	IRMA COVID-19 "Coronavirus" Data Entry - Webex information for training
6/2/2020	Email	Save the Date - Thursday June 4, 2020, COVID-19 Data entry into IRMA 10:30am
6/4/2020	Webinar	Entering COVID-19 data into IRMA
6/4/2020	Stakeholder Meeting	Visitation, Data, Day Hab, Com Hab, Fiscal Updates
6/5/2020	Email	OPWDD Incident Management oversight
6/12/2020	Email	OPWDD Request for Documentation
6/16/2020	Email	Materials from OPWDD Division of Quality Improvement 6/4/2020 training
6/17/2020	Webinar	Commissioner Kastner and the ARC NY held a webinar on COVID-19 metrics.
6/18/2020	Email	OPWDD IRMA COVID-19 new staff search functionality
6/18/2020	Email	COVID-19: Interim Visitation Guidance for Certified Residential Facilities
6/18/2020	Stakeholder Meeting	Discussion of new visitation guidance
6/19/2020	Email	COVID-19: Interim Visitation Guidance and Attestation of Participation Form for Certified Residential Facilities
6/24/2020	Email	Save the Date - Wednesday July 1, 2020, OPWDD, DQI COVID-19 IRMA Provider Training 10am
6/25/2020	Stakeholder Meeting	Visitation update, self-direction questions, stakeholder engagement, site-based respite programs
7/1/2020	Webinar	Coronavirus Event/Situation Reporting and Entry into the Incident Report and Management Application conducted with OPWDD
7/2/2020	Stakeholder Meeting	Appendix K update
7/3/2020	Email	Follow up for agencies who have not submitted-COVID-19: Interim Visitation Guidance and Attestation of Participation Form for Certified Residential Facilities
7/8/2020	Email	7/1/2020 IRMA training PDF
7/9/2020	Stakeholder Meeting	Stakeholder engagement process update, Appendix K/1115 update
7/15/2020	Email	Interim Guidance Regarding the Reopening of Day Services-Template and Attestation
7/15/2020	Webinar	How to complete the COVID-19 Life Plan/Staff Action Plan Addendum hosted by OPWDD
7/16/2020	Email	FAQ Document-Interim Guidance Regarding the Reopening of Day Services-Template and Attestation

7/16/2020	Email	REVISED-Interim Guidance Regarding the Reopening of Day Services-Template (REVISED), Attestation, and FAQ (REVISED)
7/16/2020	Stakeholder Meeting	Day services and community outings resume on 7/15/20
7/20/2020	Email	Justice Center Process Change - Justice Center Led Investigations
7/22/2020	Email	IRMA Data Revision of COVID-19 Event/Situations
7/30/2020	Stakeholder Meeting	Revised guidance documents
8/13/2020	Email	Save the Date - Thursday August 27, 2020 OPWDD, DQI COVID-19: Stop the Spread
8/13/2020	Email	Documentation Request to Agencies for Person Centered Reviews (PCR)
8/13/2020	Stakeholder Meeting	Revised appendix K, fiscal issues, day hab re-opening
8/18/2020	Stakeholder Meeting	Day programming, 20% withhold, future of day-programming
8/25/2020	Email	Interim Guidance Regarding the Reopening of Day Services Certified by NYS OPWDD
8/27/2020	Webinar	Covid containment strategies, presented by OPWDD
8/27/2020	Stakeholder Meeting	Publication of day service plans on website, revised appendix K, budget actions
9/3/2020	Email	COVID-19: Stop the Spread -- ppt from training
9/4/2020	Email	Important: Upcoming IRMA and VPCR Maintenance and WSIR Update
9/10/2020	Email	Save the Date - Fall Provider Training - October 21, 2020
9/10/2020	Stakeholder Meeting	Bureau of program certification visits, stakeholder engagement process update, flu vaccination
9/24/2020	Stakeholder Meeting	Second wave planning, waiver updates, budget update
10/2/2020	Email	Routine survey activity for non-ICF programs
10/2/2020	Email	Hotspot Provider Self-Assessment and Daily Monitoring Tools
10/8/2020	Stakeholder Meeting	Second wave planning, covid cluster monitoring
10/24/2020	Email	Important Health Advisory and Guidance for Congregate Facilities
10/25/2020	Email	Agency Notification of Site Based Certified Programs in Designated Clusters
10/25/2020	Email	OPWDD Protocol for Reporting Program Impact of COVID-19
10/25/2020	Email	Agency Notification of Site Based Certified Programs in Designated Clusters
10/29/2020	Email	Agency Notification of Site Based Certified Programs in Designated Clusters
10/29/2020	Email	Save the Date - Monday, November 9, 2020, and Important IRMA Entry Instructions
10/30/2020	Email	REVISED COMMUNICATION-Save the Date - Monday, November 9, 2020, and Important IRMA Entry Instructions
11/5/2020	Stakeholder Meeting	Guidance updates
11/10/2020	Email	Follow-up Information-COVID-19 Reporting and IRMA Entry Guidance and Proactive Testing

11/12/2020	Email	Agency Notification of Site Based Certified Programs in Designated Clusters-CHANGE 11/12/2020
11/18/2020	Email	Agency Notification of Site Based Certified Programs in Designated Clusters-CHANGE 11/18/2020
11/19/2020	Email	Agency Notification of Site Based Certified Programs in Designated Clusters-CHANGE 11/19/2020
11/19/2020	Stakeholder Meeting	Covid vaccine discussion
11/20/2020	Email	Agency Notification of Site Based Certified Programs in Designated Clusters-CHANGE 11/24/2020
11/24/2020	Email	Agency Notification of Site Based Certified Programs in Designated Clusters-CHANGE 11/24/2020
12/3/2020	Stakeholder Meeting	Vaccine, budget update
12/9/2020	Email	Save the Date - Friday, December 18, 2020, OPWDD-DQI COVID-19 Reporting and IRMA Entry
12/15/2020	Email	Agency Notification of Site Based Certified Programs in Designated Clusters-CHANGE 12/15/2020
12/22/2020	Email	Interim COVID-19 Memorandum: COVID-19 Vaccine Prioritization in Certain OPWDD Certified Residential Settings
12/23/2020	Email	12/18/2020 IRMA training Powerpoint
12/24/2020	Email	OPWDD Provider vaccine sites
12/28/2020	Email	UPDATED REGISTRATION LINK - Stony Brook University Hospital COVID Vaccine clinics-SUFFOLK COUNTY
12/28/2020	Email	Updated guidance
12/30/2020	Email	Pharmacy Partnership for Long-Term Care (LTC) Program-Provider Associations and CCOs
1/4/2021	Email	Week of January 4, 2021-Links to Vaccine Administration Scheduling
1/5/2021	Email	IMPORTANT-COVID-19 Vaccination Reporting Training-January 6, 2021
1/6/2021	Email	Multi-Agency Vaccination Data Collection System- Training PPT 2020-01-06
1/7/2021	Email	IMPORTANT Vaccination Opportunity Long Island-must sign up today January 7 for January 8.
1/7/2021	Stakeholder Meeting	Vaccine update, revised appendix K
1/8/2021	Email	Important Message to Providers Outside of NYC
1/8/2021	Email	IMPORTANT INFORMATION-NYC-Appointments available for COVID-19 Vaccinations in NYC this weekend
1/11/2021	Email	Vaccination Data Collection
1/13/2021	Email	Vaccine Consent Information for Providers
1/20/2021	Email	Issues with Vaccination Survey links
1/21/2021	Email	New vaccination survey links
1/22/2021	Email	OPWDD Vaccine Reporting Updates

1/22/2021	Email	Health Advisory: Revised Protocols for Personnel in Clinical and Direct Care Settings to Return to Work Following COVID-19 Exposure or Infection-Revised January 22, 2021
1/28/2021	Email	Agency Notification of Site Based Certified Programs in Designated Clusters-CHANGE 01/28/2021
1/31/2021	Email	Providers-Critical Information-COVID-19 Vaccinations
2/2/2021	Email	Pharmacy Partnership for Long-Term Care (LTC) Program
2/2/2021	Email	Save the Date - Thursday, February 4, 2021, COVID-19 Vaccination Reporting for Certified Site Based Day Programs and Waiver Services
2/3/2021	Email	COVID-19 Vaccination Reporting-IMPORTANT REVISED INFORMATION
2/4/2021	Email	Multi-Agency COVID-19 Vaccination Reporting: Data Entry for Day and Waiver Services
2/4/2021	Stakeholder Meeting	Data updates
2/5/2021	Email	Multi-Agency Vaccination Data Collection System-Training PPT 2021-02-04
2/9/2021	Email	Save the Date: Friday, February 12, 2021, Required COVID-19 Vaccination Reporting for CCOs for Individuals Receiving Care Management Services
2/12/2021	Email	Revised Training PPT 2021-02-12
2/16/2021	Stakeholder Meeting	Data updates
2/17/2021	Email	UPDATED: Health Advisory: Revised Protocols for Personnel in Clinical and Direct Care Settings to Return to Work Following COVID-19 Exposure or Infection
2/17/2021	Email	Suffolk County COVID-19 Vaccination PODS
2/18/2021	Email	Contact Information for LHDs from NYSACHO
3/5/2021	Stakeholder Meeting	Data overview
3/12/2021	Email	Save the Date COVID-19 Reporting and IRMA Data Entry Training
3/15/2021	Email	Weekly Vaccination Updates
3/18/2021	Email	Agency Notification -Cluster Action Initiative-CHANGE EFFECTIVE 03/22/2021
3/18/2021	Stakeholder Meeting	Data update
3/19/2021	Email	Training: COVID-19 Reporting and IRMA Data Entry-March 17, 2021
4/1/2021	Stakeholder Meeting	guidance update, appendix K extension

Appendix D – Pandemic-related costs Incurred by OPWDD from March 1, 2020 to April 1, 2021

	SFY 19-20 (only March 2020)	SFY 20-21	Total
Local Assistance - NYS Share			
HCBS Day Hab	579,014	90,410,209	90,989,223
HCBS Pre Voc	32,925	7,001,414	7,034,339
HCBS Com Hab - Hourly	143	30,673,852	30,673,995
State Plan - ICF		24,884	24,884
State Plan - Day Service		408,501	408,501
State Operating Funds			
Personal Service Costs	10,996	34,023,707	34,034,703
Non Personal Service Costs		14,759,075	14,759,075
Grand Total	***$623,078***	***$177,301,642***	***$177,924,720***

Appendix E – Impact of COVID-19 on Individuals with IDD Survey Questions and Response Demographics

Survey Questions

As you may know, there is now a law requiring the New York State Developmental Disabilities Advisory Council (DDAC) to evaluate and develop a report on New York's response to the COVID-19 pandemic for people with intellectual or developmental disabilities (IDD). The New York State Developmental Disabilities Planning Council (DDPC) is assisting the DDAC in this important work.

This survey is one of several ways the DDAC and DDC will be getting important feedback from family members and people with IDD. Your input is important to make sure the report most accurately reflects the experiences of people with IDD during the pandemic. The survey will be open until June 30 and should take about 10 minutes to complete. This survey is intended only for individuals that qualify for OPWDD services.

You only need to complete the survey if you want to, and your name will not be linked to your answers. You may choose to skip any questions that you do not want to answer. *Survey answers should be based on your experiences from March 1, 2020, to April 1, 2021.*

Thank you for participating in this survey.

Do your need this survey in another language or format? This survey can also be provided in different languages upon request. Please send all requests for translation to: Language.Access@ddpc.ny.gov or call us at 1-800-395-3372.

If you prefer a paper version of this survey or need assistance with filling it out, please send an email to: Language.Access@ddpc.ny.gov or call us at 1-800-395-3372.

1. Where did you live during March 2020 to April 2021?
    a. Home/In the community
    b. Certified Office for People with Developmental Disabilities (OPWDD) residence

<u>Home/In the Community</u>

2. Did you live at home with your family or caregiver or in the community on your own with or without supports?
    a. I lived at home with my family or caregiver.
    b. I lived independently in the community with supports.
    c. I lived independently in the community without supports.
3. Are you self-directed?
    a. Yes

b. No

4. Do you have any mental health and/or medical concerns?
    a. Yes
    b. No
5. Were you able to access OPWDD services from March 2020 to April 2021?
    a. Always
    b. Usually
    c. Sometimes
    d. Rarely
    e. Never
    f. I did not need service during that time.
6. Did the quality of OPWDD services during this time of the pandemic meet your needs?
    a. Always
    b. Usually
    c. Sometimes
    d. Rarely
    e. Never
    f. I did not need services during that time.
7. Were you able to easily access any needed Personal Protection Equipment (PPE)? Examples include masks, gloves or face shields.
    a. Always
    b. Usually
    c. Sometimes
    d. Rarely
    e. Never
8. What was your primary source of pandemic-related information regarding your disability supports and services during this time? Check all that apply.
    a. Care manager (Care Coordination Organization)
    b. Provider agency (residential, day services, community habilitation, fiscal intermediary)
    c. Family and/or friends
    d. OPWDD
    e. Self-Advocacy Association of New York State (SANYS)
    f. Other (please specify)
9. In your opinion, was the COVID-19 information…….

	Always	Usually	Sometimes	Rarely	Never
Timely?					
Easy to Understand?					
Easy to get?					

10. Were you aware of the rules that service providers were supposed to follow to prevent you from getting COVID-19? These rules included things like hand washing, mask wearing and social distancing.
    a. Yes
    b. No
    c. Unsure
11. Do you feel the rules put in place by the State to stop the spread of COVID-19 were enough to keep you safe during this time?
    a. Yes
    b. No
    c. Unsure
12. Do you feel the rules were made in time to keep you safe?
    a. Yes
    b. No
    c. Unsure
13. Do you feel your service provider followed COVID-19 safety rules during this time?
    a. Yes
    b. No
    c. Unsure
14. During this time, did the service provider notify you quickly if you had been near someone with COVID-19?
    a. Yes, I was notified when I had been near someone with COVID.
    b. No, they did not notify me when I had been near someone with COVID.
    c. I am not aware that I was ever near someone with COVID.
15. Do you know if the service provider staff was regularly tested for COVID-19 once testing became widely available?
    a. Yes
    b. No
    c. Unsure
16. If you stopped receiving services during this time, were you kept updated when services would start again?
    a. Yes
    b. No
    c. My services never stopped.
    d. I was not receiving services during that time.
17. Have all services documented in your Life Plan that were paused during March 2020 through April 2021 started again?
    a. Yes
    b. No
    c. Unsure

18. If you needed to be hospitalized during this time period of the pandemic, did you receive care that met your specific needs?
    a. Yes
    b. No
    c. I did not need to be hospitalized from March 2020 to April 2021.

    If no, please describe:
19. Were you satisfied with how often your Care Manager checked in with you to see if you needed any help during this time with things like getting food, medications, masks, etc.?
    a. Completely satisfied
    b. Very satisfied
    c. Somewhat satisfied
    d. Slightly satisfied
    e. Not satisfied at all
20. Did you have any needs that the Care Manager was not able to help with?
    a. Yes
    b. No
21. Please describe any of your needs that were not met during this time.
22. Overall, did you feel safe and supported during March 2020 through April 2021 of the pandemic?
    a. Yes
    b. No
    c. Unsure

<u>Certified Residence</u>

23. Are you self-directed?
    a. Yes
    b. No
24. Do you have any mental health and/or medical concerns?
    a. Yes
    b. No
25. What was your primary source of pandemic-related information regarding disability supports and services during this time? Check all that apply
    a. Residential service provider
    b. OPWDD
    c. Family and/or friends
    d. Self-Advocacy Association of New York State (SANYS)
    e. Other (please specify)
26. In your opinion, was the COVID-19 information…….

	Always	Usually	Sometimes	Rarely	Never
Timely?					
Easy to Understand?					

Easy to get?					

27. How were you able to stay in touch with your family members during the time period when no visits were allowed? Check all that apply.
    a. Staff assisted with virtual visits or phone calls.
    b. I used the phone, computer, iPad or another device to stay in touch with family members.
    c. Staff called or emailed with updates.
    d. I was not able to stay in touch with my family.
    e. Other (please specify)
28. Were you aware if the Direct Service Providers (DSPs) in your home were regularly tested for COVID-19 once testing became widely available?
    a. Yes
    b. No
    c. Unsure
29. Were you able to easily get any needed Personal Protective Equipment (PPE) during this time? Examples include masks, gloves or face shields.
    a. Always
    b. Usually
    c. Sometimes
    d. Rarely
    e. Never
30. Were you aware of the rules put in place in your home to stop COVID-19 from spreading during this time? For example: handwashing, mask wearing, social distancing, PPE
    a. Yes
    b. No
    c. Unsure
31. Do you feel the rules put in place by the State to stop the spread of COVID were enough to keep you safe during this time?
    a. Yes
    b. No
    c. Unsure
32. Do you feel the rules were made in time to keep you safe?
    a. Yes
    b. No
    c. Unsure
33. Do you feel that staff in your home followed the rules?
    a. Yes
    b. No
    c. Unsure
34. Were you quickly told when you had been near someone with COVID-19?
    a. Yes, I was notified when I had been near someone with COVID.

b. No, I was not notified when I had been near someone with COVID.
c. I am not aware that I was ever near someone with COVID.

35. Were people able to isolate inside of your home if they got COVID-19 during this time?
    a. Yes
    b. No
    c. Unsure
36. If not, were people able to stay in places outside of your home if they got COVID-19?
    a. Yes
    b. No
    c. Unsure
37. Did you agree with OPWDD guidance on visitation for certified residences?
    a. Strongly agree
    b. Agree
    c. Neither agree or disagree
    d. Disagree
    e. Strongly disagree
    f. I did not receive visitation guidance

    Please explain.
38. Did your opinion of OPWDD visitation guidance change as places around you started to move away from lock-down?
    a. Yes, my opinion was better.
    b. Yes, my opinion was worse.
    c. No, my opinion did not change.
    d. I did not receive visitation guidance.

    Please explain.
39. Was the information that you received on visits…….

	Always	Often	Sometimes	Rarely	Never
Easy to Understand?					
Timely?					
Easy to get?					

40. If you needed to be hospitalized during this time period of the pandemic, did you receive care that met your specific needs?
    a. Yes
    b. No
    c. I did not need to be hospitalized from March 2020 to April 2021

    Please describe.
41. Overall, did you feel safe and supported in your home form March 2020 to April 2021?
    a. Yes
    b. No
    c. Unsure

All

42. Did you receive timely information on how and where to access the following in either the certified residence or the community?

	Yes	No	Unsure	N/A
Vaccinations				
Boosters				
Testing				

43. Were enough supports available to respond to your following needs from March 2020 to April 2021?

	Yes	No	Unsure	N/A
Mental Health				
Physical Health				
Social Interaction				

44. Please select the top five (5) ways that New York can improve its response related to individuals with IDD during a future public health crisis.
    a. Get information faster
    b. Make information easier to understand including materials written in plain language or other languages
    c. Policies with special thought given to individuals with IDD
    d. Prioritize individuals with IDD for vaccinations
    e. Prioritize family members/caregivers of individuals with IDD for vaccinations
    f. Visitation policies that are easy to understand
    g. Prioritize OPWDD residences for PPE distribution
    h. Make testing requirements the same for all people living and working in a group home
    i. Instructions for quarantining and isolating within a group home
    j. Places to quarantine in OPWDD residences
    k. Instructions for hospital visits that are specialized for individuals with IDD
    l. More flexibility in the delivery of DD services
    m. Other (please specify)
45. Is there anything else you would like to share about New York's response to COVID-19 in relation to individuals with IDD?
46. How has the pandemic impacted your life?

Demographic Information

47. What is your race and/or ethnicity?
    a. White or Caucasian (i.e. German, Irish, English, Italian, Polish, French)
    b. Black or African American (i.e. Jamaican, Haitian, Nigerian, Ethiopian, Somalian)
    c. Hispanic, Latin or Spanish Origin (i.e. Mexican, Mexican-American, Puerto Rican, Salvadoran, Dominican)
    d. Asian (i.e. Chinese, Korean, Japanese, Filipino, Vietnamese)

e. South Asian (i.e. Pakistani, Indian, Bangladeshi)
f. American Indian or Alaska Native
g. Middle Eastern or North African (i.e. Afghani, Lebanese, Iranian, Egyptian, Syrian)
h. Native Hawaiian or other Pacific Islander
i. I prefer not to answer.
j. Another race/ethnicity (please specify)

48. What is your gender?
    a. Female
    b. Male
    c. Nonbinary
    d. Prefer not to say
    e. Prefer to self-describe
49. Where do you live?
    a. A big city (i.e. Albany, buffalo, New York City, Rochester)
    b. A medium-sized city or suburb (i.e. Binghamton, Cortland, Schenectady, Utica)
    c. A smaller, rural area (i.e. North Country)
50. In which OPWDD Developmental Disabilities Region do you live?
    a. Western New York and Finger Lakes
    b. New York City
    c. Long Island
    d. Central New York, Southern Tier, and North Country
    e. Capital Region and Hudson Valley
    f. Unsure

Response Demographics

What is your race and/or ethnicity?

Answer Choices	Responses	
White or Caucasian (i.e. German, Irish, English, Italian, Polish, French)	75.09%	211
Black or African American (i.e. Jamaican, Haitian, Nigerian, Ethiopian, Somalian)	6.76%	19
Hispanic, Latin or Spanish Origin (i.e. Mexican, Mexican-American, Puerto Rican, Salvadoran, Dominican)	5.34%	15
Asian (i.e. Chinese, Korean, Japanese, Filipino, Vietnamese)	1.78%	5
South Asian (i.e. Pakistani, Indian, Bangladeshi)	1.42%	4
American Indian or Alaska Native	0.71%	2
Middle Eastern or North African (i.e. Afghani, Lebanese, Iranian, Egyptian, Syrian)	0.36%	1
Native Hawaiian or other Pacific Islander	0.00%	0
I prefer not to answer.	6.41%	18
Another race/ethnicity (please specify)	2.14%	6

What is your gender?

Answer Choices	Responses	
Female	48.21%	135
Male	45.36%	127
Nonbinary	0.36%	1
Prefer not to say	5.00%	14
Prefer to self-describe	1.07%	3

Where do you live?

Answer Choices	Responses	
A big city (i.e. Albany, Buffalo, New York City, Rochester)	27.34%	76
A medium-sized city or suburb (i.e. Binghamton, Cortland, Schenectady, Utica)	38.85%	108
A smaller, rural area (i.e. North Country)	33.81%	94

In which OPWDD Developmental Disabilities Region do you live?

Answer Choices	Responses	
Western New York and Finger Lakes	10.99%	31
New York City	16.67%	47
Long Island	25.89%	73
Central New York, Southern Tier, and North Country	23.40%	66
Capital Region and Hudson Valley	19.50%	55
Unsure	3.55%	10

Appendix F - Impact of COVID-19 on Families of Individuals with IDD
Survey Questions and Response Demographics

Survey Questions

As you may know, there is now a law requiring the New York State Developmental Disabilities Advisory Council (DDAC) to evaluate and develop a report on New York's response to the COVID-19 pandemic for people with intellectual or developmental disabilities (IDD). The New York State Developmental Disabilities Planning Council (DDPC) is assisting the DDAC in this important work.

This survey is one of several ways the DDAC and DDC will be getting important feedback from family members and people with IDD. Your input is important to make sure the report most accurately reflects the experiences of people with IDD during the pandemic. The survey will be open until June 30 and should take about 10 minutes to complete. This survey is intended only for individuals that qualify for OPWDD services.

You only need to complete the survey if you want to, and your name will not be linked to your answers. You may choose to skip any questions that you do not want to answer. *Survey answers should be based on your experiences from March 1, 2020, to April 1, 2021.*

Thank you for participating in this survey.

Do your need this survey in another language or format? This survey can also be provided in different languages upon request. Please send all requests for translation to: Language.Access@ddpc.ny.gov or call us at 1-800-395-3372.

If you prefer a paper version of this survey or need assistance with filling it out, please send an email to: Language.Access@ddpc.ny.gov or call us at 1-800-395-3372.

1. Where did your family member with IDD live during the COVID-19 pandemic?
    a. Home/In the community
    b. Certified Office for People with Developmental Disabilities (OPWDD) residence

Home/In the community

2. Does your family member with IDD live at home with you or independently in the community with supports?
    a. My family member lives at home with me.
    b. My family member lives independently in the community with supports.
3. Is your family member with IDD self-directed?
    a. Yes

b. No

4. Does your family member with IDD have any complex behavioral and/or medical concerns?
    a. Yes
    b. No
5. Were you able to access services for your family member with IDD during the pandemic?
    a. Always
    b. Usually
    c. Sometimes
    d. Rarely
    e. Never
    f. Never requested services
6. Were you able to access back up support if you were unable to care for your family member due to work commitments, contracting COVID-19 or other reasons?
    a. Always
    b. Usually
    c. Sometimes
    d. Rarely
    e. Never
    f. I did not need back up support.
7. For you to safely care for your family member with IDD, what barriers, if any, did you have in accessing PPE? Check all that apply.
    a. Could not locate PPE
    b. Needed help with financing PPE (self-directed budget flexibility, support from certified residence when loved one being care for at home, etc.)
    c. Lack of clear guidance on what PPE to use
    d. N/A – I did not have any barriers in accessing PPE
    e. Other (please specify)
8. What was your primary source of pandemic-related information regarding disability supports and services? Check all that apply.
    a. Care manager (Care Coordination Organization)
    b. Provider agency (residential, day services, community habilitation, fiscal intermediary)
    c. OPWDD
    d. Other (please specify)
9. In your opinion, was the COVID-19 information related to individual with IDD…..

	Always	Usually	Sometimes	Rarely	Never
Timely?					
Easy to understand?					
Accessible?					

Consistent with other guidances/directives					

10. Were you aware of the specific preventative protocols put in place by your family member with IDD's service provider(s) to minimize COVID-19 exposure (i.e. handwashing, mask wearing, social distancing, PPE)?
    a. Yes
    b. No
    c. Unsure
11. Do you feel the protocols were adequate to provide your family member with safety?
    a. Yes
    b. No
    c. Unsure
    d. N/A
12. Do you feel the protocols were issued timely enough to provide for your family member with IDD's safety?
    a. Yes
    b. No
    c. Unsure
    d. N/A
13. Do you feel the service provider adhered to the protocols?
    a. Yes
    b. No
    c. Unsure
    d. N/A
14. Did the service provider notify you in a timely way when an exposure occurred?
    a. Yes
    b. No
    c. I am not aware of any exposure.
15. Were you aware if the service provider staff was regularly tested for COVID-19 once testing became widely available?
    a. Yes
    b. No
    c. Unsure
16. If your family member with IDD experienced a service interruption, were you kept updated regarding when onsite and/or in-person services would resume?
    a. Yes
    b. No
    c. N/A
17. Have all the services documented in your family member with IDD's Life Plan resumed?
    a. Yes

b. No
c. Unsure

18. Did you received information regarding your visitation rights should your family member with IDD require hospitalization?
    a. Yes
    b. No
    c. N/A
19. Did you understand your visitation rights should your family member with IDD require hospitalization?
    a. I did not understand at all.
    b. I slightly understood.
    c. I moderately understood.
    d. I mostly understood.
    e. I completely understood.
    f. N/A
20. Were you satisfied with the frequency that your Care Manager (CCO) checked in with you to determine any unmet needs during the pandemic such as access to food, medications, safe living environment, etc.?
    a. Completely satisfied
    b. Very satisfied
    c. Somewhat satisfied
    d. Slightly satisfied
    e. Not satisfied at all
21. Did you have any needs that the Care Manager was not able to assist with?
    a. Yes
    b. No
22. Please describe your unmet needs.
23. Is your family member with IDD school age (3 to 21)?
    a. Yes
    b. No
24. Were you able to access respite or community habilitation during school closures?
    a. Always
    b. Usually
    c. Sometimes
    d. Rarely
    e. Never
    f. Not required

<u>Certified Residence</u>

25. Is your family member with IDD self-directed?
    a. Yes
    b. No

26. Does your family member with IDD have any complex behavioral and/or medical concerns?
    a. Yes
    b. No
27. What was your primary source of pandemic-related information regarding your family member with IDD's disability supports and services?
    a. Residential service provider
    b. OPWDD
    c. Other (please specify)
28. In your opinion, was the COVID-19 information related to individuals with IDD…..

	Always	Often	Sometimes	Rarely	Never
Timely?					
Easy to Understand?					
Accessible?					
Consistent with other guidance/directives?					

29. How were you updated on your family member with IDD during the period in which no visits were allowed? Check all that apply.
    a. Staff assisted with virtual visits or phone calls.
    b. Family member with IDD independently made virtual visits or phone calls.
    c. Staff called or emailed regularly.
    d. I did not receive regular updates.
    e. Other (please specify)
30. Were you aware if the residence staff were regularly tested for COVID-19 once testing became widely available?
    a. Yes
    b. No
    c. Unsure
31. Were you aware of the specific preventative protocols put in place in your family member with IDD's certified setting to minimize COVID-19 exposure between residents (i.e. hand washing, mask wearing, social distancing, PPE)?
    a. Yes
    b. No
    c. Unsure
32. Do you feel the protocols were adequate to provide your family member with safety?
    a. Yes
    b. No
    c. Unsure
33. Do you feel the protocols were issued timely enough to provide for your family member with IDD's safety?
    a. Yes

b. No
c. Unsure

34. Do you feel the residence adhered to the protocols?
    a. Yes
    b. No
    c. Unsure
35. Were you notified in a timely way when an exposure occurred?
    a. Yes
    b. No
    c. I am not aware of any exposure.
36. Were you informed about the steps taken to reduce your family member's risk of contracting COVID-19 such as masking, social distancing, PPE, quarantine or isolation?
    a. Yes
    b. No
37. Was your provider agency able to use facilities inside of the residence to isolate residents, who contracted COVID-19?
    a. Yes
    b. No
    c. Unsure
38. Was your provider agency able to use facilities outside of the residence to isolate residents, who contracted COVID-19?
    a. Yes
    b. No
    c. Unsure
39. Did you agree with OPWDD certified residence visitation guidance?
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree
    f. I did not receive visitation guidance

    Please explain.
40. Did your opinion of OPWDD visitation guidance change as communities started to emerge from lock-down?
    a. Yes, my opinion became more favorable.
    b. Yes, my opinion became less favorable.
    c. No, my opinion did not change.
    d. N/A, I did not receive guidance.

    Please explain.
41. Was the visitation guidance that you received…..

	Always	Often	Sometimes	Rarely	Never	N/A

Easy to understand?						
Timely?						
Accessible?						

All

42. Did you receive timely information on how and where to access the following in either the certified residence or in the community?

	Yes	No	Unsure	N/A
Vaccinations				
Booster				
Testing				

43. Were sufficient supports available to respond to the following needs of your family member with IDD during the pandemic?

	Yes	No	Unsure	N/A
Mental health				
Physical health				
Behavioral health				
Social interaction				

44. Are sufficient supports available to respond to the following needs of your family member with IDD currently?

	Yes	No	Unsure	N/A
Mental health				
Physical health				
Behavioral health				
Social interaction				

45. Please select the top five (5) ways that New York can improve its response related to individuals with IDD during a future public health crisis.
    a. More timely release of information and guidance
    b. More accessible information and guidance sharing, including materials in multiple languages
    c. Policies with special consideration given to individuals with IDD
    d. Prioritize individuals with IDD for vaccinations
    e. Prioritize family members/caregivers of individuals with IDD for vaccinations
    f. Clear visitation policies, considering special needs of individuals with IDD
    g. Prioritize OPWDD residences for PPE distribution
    h. Create universal testing protocols for individuals living in and staff working in group homes
    i. Guidance for quarantining and isolating within a group home

j. Hospitalization and/or discharge policies during a public health crisis that are specialized for individuals with IDD
k. More flexibility in the delivery of DD services
l. Other (please specify)

46. Is there anything else you would like to share about New York's response to COVID-19 in relation to individuals with IDD?
47. How has the pandemic impacted your life?

<u>Demographic Information</u>

48. What is your race and/or ethnicity?
    a. White or Caucasian (i.e. German, Irish, English, Italian, Polish, French)
    b. Black or African American (i.e. Jamaican, Haitian, Nigerian, Ethiopian, Somalian)
    c. Hispanic, Latin or Spanish Origin (i.e. Mexican, Mexican-American, Puerto Rican, Salvadoran, Dominican)
    d. Asian (i.e. Chinese, Korean, Japanese, Filipino, Vietnamese)
    e. South Asian (i.e. Pakistani, Indian, Bangladeshi)
    f. American Indian or Alaska Native
    g. Middle Eastern or North African (i.e. Afghani, Lebanese, Iranian, Egyptian, Syrian)
    h. Native Hawaiian or other Pacific Islander
    i. I prefer not to answer.
    j. Another race/ethnicity (please specify)
49. What is your gender?
    a. Female
    b. Male
    c. Nonbinary
    d. Prefer not to say
    e. Prefer to self-describe
50. Where do you live?
    a. A big city (i.e. Albany, buffalo, New York City, Rochester)
    b. A medium-sized city or suburb (i.e. Binghamton, Cortland, Schenectady, Utica)
    c. A smaller, rural area (i.e. North Country)
51. In which OPWDD Developmental Disabilities Region do you live?
    a. Western New York and Finger Lakes
    b. New York City
    c. Long Island
    d. Central New York, Southern Tier, and North Country
    e. Capital Region and Hudson Valley
    f. Unsure

Response Demographics

What is your race and/or ethnicity?

Answer Choices	Responses	
White or Caucasian (i.e. German, Irish, English, Italian, Polish, French)	66.25%	642
Black or African American (i.e. Jamaican, Haitian, Nigerian, Ethiopian, Somalian)	4.75%	46
Hispanic, Latin or Spanish Origin (i.e. Mexican, Mexican-American, Puerto Rican, Salvadoran, Dominican)	4.33%	42
Asian (i.e. Chinese, Korean, Japanese, Filipino, Vietnamese)	12.90%	125
South Asian (i.e. Pakistani, Indian, Bangladeshi)	0.52%	5
American Indian or Alaska Native	0%	0
Middle Eastern or North African (i.e. Afghani, Lebanese, Iranian, Egyptian, Syrian)	0%	0
Native Hawaiian or other Pacific Islander	0%	0
I prefer not to answer.	8.15%	79
Another race/ethnicity (please specify)	3.10%	30

What is your gender?

Answer Choices	Responses	
Female	76.23%	741
Male	16.98%	165
Nonbinary	0.41%	4
Prefer not to say	5.66%	55
Prefer to self-describe	0.72%	7

Where do you live?

Answer Choices	Responses	
A big city (i.e. Albany, Buffalo, New York City, Rochester)	40.52%	387
A medium-sized city or suburb (i.e. Binghamton, Cortland, Schenectady, Utica)	38.85%	371
A smaller, rural area (i.e. North Country)	20.63%	197

In which OPWDD Developmental Disabilities Region do you live?

Answer Choices	Responses	
Western New York and Finger Lakes	17.13%	168
New York City	25.99%	255
Long Island	14.17%	139
Central New York, Southern Tier, and North Country	15.80%	155
Capital Region and Hudson Valley	24.97%	245
Unsure	1.94%	19

NEW YORK STATE OF OPPORTUNITY.
Office for People With Developmental Disabilities

KATHY HOCHUL
Governor

KERRI E. NEIFELD
Commissioner

ROGER BEARDEN, J.D.
Executive Deputy Commissioner

November 10, 2022

Dear Developmental Disabilities Advisory Council Members:

Thank you for the opportunity to provide feedback to your report titled "Assessing New York State's Response to COVID-19 for People with Intellectual and Developmental Disabilities." We appreciate the time and effort that went into the report and appreciate the continued collaboration with Developmental Disabilities Advisory Council (DDAC) and the Developmental Disabilities Planning Council (DDPC) as we seek to learn from our experience in combating COVID-19.

As you are aware, the COVID-19 global pandemic presented an enormous challenge for the Office for People With Developmental Disabilities (OPWDD), our not-for-profit service providers, and people with intellectual and development disabilities and their families. From the outset, OPWDD was committed to working with federal and state public health partners to preserve the health and safety of the people we serve. Throughout the pandemic, difficult decisions were made to best protect the individuals we serve guided by the best available data, guidance from public health experts and in continued communication with our stakeholders. OPWDD is proud of the numerous actions we took to mitigate the risks of the pandemic and the extraordinary efforts of state and nonprofit staff to keep people safe, often at risk to their own health and safety.

This report frequently references feedback from focus groups and individual-specific comments which appear to have been selectively chosen with an unbalanced emphasis towards describing negative experiences. Also, it is worth noting the information gathered via the voluntary surveys may have generated biased results because those who chose to respond were not necessarily representative of the population served by OPWDD. We note that the Black and Hispanic communities seem significantly under-represented among DDAC survey respondents, in comparison to OPWDD's overall service system. The Asian and White communities appear over-represented. From a geographic standpoint, several parts of the state were under-represented, while OPWDD Region 3 (Capital District, Taconic, and Hudson Valley) was over-represented in comparison with our overall service system.

We appreciate the disclosure in the Forward section of the report which makes it clear this report is not meant to be a scientific study with statistical validation. We also appreciate the well-intentioned discussion of unique individual difficulties and perceptions, as every voice should be considered as OPWDD moves forward in accessing possible ways in which the system could improve.

OPWDD recognizes that measures it undertook created significant hardships for people with developmental disabilities and their families. The decision to suspend congregate day habilitation programs reduced people's access to vital services. The limitation on visitation in group homes prevented families from seeing their loved ones. The closure of these programs, like the closure of schools, day care facilities and other congregate settings, disrupted the lives of the people who attend such programs and those of the family members who cared for them. These decisions were not made lightly, but they were essential to protect lives and contain the spread of the virus. Although the information gathered for the report speaks to the pain and hardship of these contact restrictions, we believe that the report could have better acknowledged the prioritizations and sacrifices that must be made in response to a global pandemic.

OPWDD's efforts to combat COVID engaged our own staff, our not-for-profit service providers, the state's public health agency, and the federal government. These efforts included creation of new COVID data collection and reporting mechanisms, training hundreds of contact tracers, developing dozens of guidance documents, submitting multiple emergency waiver amendments to the federal Centers for Medicare and Medicaid Services, and working to assure appropriate infection control policies and practices in over 7,000 certified residences across the state. In several parts of the report, it seems to suggest OPWDD should have taken on a greater role in the realm of community public health oversight, but there are limitations to OPWDD's statutory authority which does not cover activities outside of its certified programs. External approvals at times caused delays but were unavoidable; for example, OPWDD could not unilaterally implement the day habilitation retainer payment program because it required federal review and consent. Although we understand there were frustrations for people with developmental disabilities, their families, and our provider community, many challenges were overcome collaborating with multiple partners in confronting an unprecedented global pandemic.

Having gone through the experience of developing numerous new standards and guidelines, should a similar pandemic occur, OPWDD will certainly be well-prepared to take immediate and appropriate actions. Nevertheless, we are not assuming our past experiences have left us completely prepared. In fact, many of the recommendations contained in this report are mirrored in the just released OPWDD Strategic Plan, such as efforts to improve workforce retention, improve service access in underserved communities, enhance communications, and more. OPWDD will utilize the contents of this report to assist with future planning and looks forward to working together with DDAC and DDPC in our quarterly meetings towards our mutual goal of better serving New Yorkers with developmental disabilities.

Sincerely,

Kerri E. Neifeld
Commissioner